



Prototyping a Collective

On ethnography, design, and use of a personal health record

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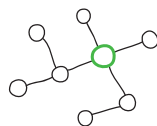
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PhD thesis

Tariq Osman Andersen

PROTOTYPING A COLLECTIVE

On ethnography, design, and use of a personal health record



CITH

Co-constructing IT and Healthcare

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Prototyping a Collective

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Abstract

The challenge for design of information technology is typically modelled as a matter of developing better ways of bridging between users and designers. This is often referred to as the ‘requirements problem’ or discussed in terms of ‘implications for design’. Since the 1970s, various fields of interdisciplinary research have addressed this challenge in particularly two ways. Researchers in Participatory Design have created methods, tools, and techniques that actively involve users while researchers in the neighbouring field of Computer-Supported Cooperative Work (CSCW) have employed ethnography in direct and indirect ways to mediate between users and designers. However, this research misses to take serious that, which it is all about; *the future use-situation*. Instead of going ‘full circle’ by integrating ethnography and design at use-time, the problem of developing ‘better’ technologies is treated as epistemic and as a matter of making good representations work by envisionment or simulation. Users and use becomes something that is left for others to create after the researchers have been involved.

The thesis consists of five research papers and an extended synopsis that suggests re-framing the problem from being a matter of improving user-designer relations to critically co-exploring by performing future situations of use. The work presented comes out of a cross-institutional and interdisciplinary research and development project in cardiac healthcare in the Copenhagen Region, Denmark. From 2008-11, the CITH project has engaged more than 50 patients and relatives and 20 health professionals in research and co-design of prototypes of a web-based personal health record, *myRecord*.

By multiple method experiments and by drawing on posthuman theory and performative ontology such as actor–network theory and later writings in science and technology studies, an alternative design research approach is suggested: ‘Prototyping a Collective’ seeks to overcome the problem of mediating user-designer relations by the collaborative making of socio-material assemblages of ethnography, design, and use. The approach is developed from five propositions; (1) Aspire to realistic lines between design and ethnography, (2) work towards convergence of design and use, (3) consider participatory design as ethnography, (4) employ design interventions as a strategy of multiple becomings, and (5) engage proactively with ‘practicalities’ of the project.

Prototyping a Collective is an interdisciplinary approach to studying that, which we want to create. It is my suggestion to work towards the making of method assemblages where a collective of human and non-human actors collaborate in performing while designing future situations of use.

Acknowledgements

At the IT University of Copenhagen in 2004, I was lucky that a student counsellor suggested me to contact Finn Kensing for supervision. Since then, Finn has critiqued and advised me on multiple projects, introduced me to the field of Participatory Design, and continually encouraged me along the way on the CITH project. I am extremely grateful for that, thank you Finn!

On my first conference, the ECSCW'05 in Paris, I met Jens Pedersen and Nis Johannsen who motivated me to think of doing a PhD. Thank you Jens, in particular, for countless inspiring discussions and for pushing my scholarly development. In the same vein, I am indebted and very fortunate to have met Joachim Halse, because of whom I wouldn't have dared making the philosophical gearshift, which drives the main argument I put forward in this thesis.

I would like to express my great appreciation to everyone who participated on the CITH project, which financially have been made possible by funding from The Danish Council for Strategic Research, grant #2106-07-0017. I am grateful, especially to all involved patients and relatives for inviting me into your homes and letting me participate in healthcare meetings as well as for your own active partaking in design workshops and design interventions. Similarly, I need to thank the CITH health professionals for their professionalism and valuable collaboration; Helen Høgh Petersen, Mie Christa Jensen Larsen, Ea Lorentzen, Jesper Hastrup Svendsen, and Olav Wendelboe Nielsen. I also need to make clear, that without the brilliant person and web developer Anselm Christophersen, we would have not succeeded making CITH what it has become; thanks for putting tremendous effort and good vibes into the project. Thank you Jørgen Bansler, Peter Danholt, Bill Gaver, Mike Michael, Nina Wakeford, and Alex Wilkie for support on article drafts, and in particular Pernille Bjørn for significant learning from writing the IJMI journal article together.

Thank you Erik Frøkjær and Kasper Hornbæk for support and making the HCC research group at DIKU, the University of Copenhagen, an inspirational and outmost pleasurable environment to work in. I am very happy to have been surrounded by such intelligent and positive company of everyone in the HCC group, especially Karen Marie Lyng and Martin Scheil Corneliussen, but also Rikke Lauth in the Center for IT Innovation. I am privileged to have met Balder Onarheim, Naja Holten Møller, Signe Yndigegn and Emilie Møllenbach with whom I have enjoyed super company and friendship a long the way, not to mention the many lunches, coffees and Friday beers.

In this shortened list, still two persons are missing; Troels Mønsted and Jonas Moll who have made the PhD journey one of the greatest peaks in my life so far. Troels, an official compliment to your person hood and thanks for the countless discussions and inspiring collaboration but also for sharing so many memorable experiences inside and outside the academic environment. Jonas, I owe you the most, since I would have not made it this far in all aspects without you being convinced to do a (joint) PhD back in the cafeteria and on the bike rides to and from Capgemini in 2008. That is, I could have never done this thesis without your amazing companionship. I am already looking forward to the next jungles and rivers to explore and feel comfortable that anything is possible when you are on board the ship.

Above all, I'm continually thankful to Mette-Sofie for your warm support, love, and for keeping up with all the ways in which I have been 'away', but also for listening and creating happiness around me. In this sentence I would have liked to include my father and my amazing mother, who are my role models, still, and who I would like to dedicate this thesis to.

It is to my luck, I have met you all. Thank you,
Tariq

“When I drive from Tokyo to Kyoto, as soon as I turn the ignition key of my Nissan, I mobilize all the engineers who designed my car, the researchers who studied the resistance of materials, the firms that explored the deserts of the Middle-East and drill for oil, the refineries that produce petrol, the civil engineering firms that built the highways and maintain them, the driving school and its teacher who taught me to drive, the governments that drafted and issued traffic laws, the police who enforce them, and the insurance companies that help me to face my responsibilities.

The simple act of turning an ignition key and driving from Tokyo to Kyoto mobilizes an extended network of human and non-human entities that participate, as many and yet as one, in this very ordinary action of transporting me from Tokyo to Kyoto. This action is collective.” (Callon, 2004)

Introduction

This PhD dissertation is about design research. More exactly it is about method experiments with participatory design and ethnography. The central concern, examined in five articles and elaborated in this extended summary, relates to the broad methodological problem of; *how can we study, that which we want to create?* This is somehow an oxymoron, a contradiction in terms; *because how can we study something that we have not yet created? Who are ‘we’? Are ‘we’ a collective of humans and things?*

Before getting too philosophical, at this point, I would like to keep this question to the thesis as a whole and use the introduction to situate and position the thesis.

The work presented here, has been part of a research and development project in healthcare in the period 2008-2011 in Copenhagen, Denmark. CITH (Co-constructing IT and Healthcare) is a cross-institutional¹ and interdisciplinary² project, funded by the Danish Council for Strategic Research grant #2106-07-0017. In that part of the project, which I have been part of, more than 50 patients (all anonymised in this thesis) and relatives and more than 20 health professionals have participated and contributed to the

¹ CITH is a collaboration between the University of Copenhagen, the Technical University of Denmark, Copenhagen Business School, the IT University of Copenhagen, Copenhagen University Hospital and Bispebjerg Hospital. See more on www.cith.dk.

² The 12 researchers involved comprises interdisciplinary research (cardiology, health informatics, computer science, sociology, and design research): Mie Christa Jensen Larsen, Helen Høgh Petersen, Pernille Bjørn, Olav Wendelboe Nielsen, Jesper Hastrup Svendsen, Erling C. Havn, Kjeld Schmidt, Jørgen Bansler, Finn Kensing (head of project), Troels Mønsted, Jonas Moll and myself. This group of people comprises multiple disciplines: cardiology, health informatics, computer science, sociology, and design research.

development of six consecutive versions of a web based prototype of a personal health record; myRecord.

In the Copenhagen region in Denmark heart patients with an implanted ICD (advanced pacemaker) receive distributed care according to medical specialty. This means that the Heart Centre at the Copenhagen University Hospital is responsible for ICD-related care such as implantation and continual telemonitoring of ICD-devices, whereas the local hospitals are responsible for the medical care. The network of health professionals who monitor and deliver healthcare is therefore inter-institutionally distributed with patients spending most of their time away from the hospitals. This disconnection of time and place challenges communication. The distributed network of heterogeneous actors is the starting point of design and research on the CITH project.

The fields of research from where this thesis departs are computer-supported cooperative work (CSCW) and participatory design. CSCW has since the mid-1980s been employing social scientific practices to accommodate the problem of mediating between users (what do they want?) and designers (what could we make?). *“CSCW should be conceived of as an endeavour to understand the nature and requirements of cooperative work with the objective of designing computer-based technologies for cooperative work arrangements”* (Schmidt and Bannon, 1992). Since then, the field has expanded to encompass a range of other approaches and has spread into new domains including online computer games. Closely related to CSCW is participatory design, which started around the same time. Participatory design springs from a political and democratic movement as *“to formulate a research approach for democratization systems design”* (Ehn, P. and Kyng, 1987). Inherent in this approach is also the methodological concern of relating users with designers. But while CSCW research typically employs ethnography as a means to mediate, the field of participatory design has been particularly successful in crafting methods, tools, and techniques to actively engage participants in overcoming the user-designer relation in systems design.

However, there is also a second relation, which is modelled and performed by CSCW ethnographies and participatory design methods; namely that of present and future, or as sometimes called; design and use. Making a very general assumption, CSCW typically considers the relation between present and future as a one-way street i.e. *we have to understand what the problem is before we can design anything useful*. Participatory design typically approaches the problem of relating design and use by actively involving stakeholders in designing and envisioning use of information technology.

But what if we take into account, these general assumptions of what CSCW researchers and participatory designers do? What happens with that, which it is all argued to be about; the future use situation; the useful technologies and the better world? Then what? Methods that operate in terms of ‘we have to mediate between users and

designers and between design and use', I would say, miss the most important thing; the future, or the use-time itself. 'Use', *typically* becomes something that is left to after the researchers have been involved. Successful use is then something that the 'users' have to create. Use, then, is somehow downplayed and not integrated in the research and design endeavour. Therefore, with this thesis, I shall present one way that we (the CITH project) have dealt with integrating use with design and ethnography. What becomes present is that in realistic terms, it is just as much a practical, somehow mundane achievement as it is a philosophical or methodological one.

Now again, this was rather philosophical. But what follows is a much more grounded introduction, description and discussion of what research and design experiments I have taken part in. It includes all the practical steps and the method experiments carried out to be able to make six propositions and the final contribution framed as 'prototyping a collective'.

Structure of the thesis

This extended summary draws together three types of texts to make one final argument; literature reviews, process and case descriptions, and five papers that are attached. Since the main argument is inseparable from and closely tied to the entire research process I have chosen to use the developments in the process as a structure for the summary. The summary is divided in three parts following the versions of the prototypes that have been designed and used on the project; part 1.0 and 2.0 and 3.0:

Part 1.0 (October 2008 to December 2009)

- Introduction to CSCW and Participatory Design
- Case: The referral study
- Description of v. 1.0 of the prototype, *Diary*

Part 2.0 (January 2010 to September 2010)

- Description of v. 2.0 of the prototype, *Inform*
- Description of main process activities
- Introduction to the field of design research
- (Un)Productive tensions A and B [paper 1-4]

Part 3.0 (October 2010 to September 2011)

- Introduction to STS and ANT
- Introduction to STS-design methods discourse
- Description of v. 3.0 of the prototype, *myRecord*
- Case; Prototyping Patient 2.0 [paper 5]
- Contribution: 'Prototyping a Collective'

In each part I make an introduction to the main research fields that inspired the work and the experiments made; CSCW, ethnography and workplace studies; participatory design; design research; STS and ANT; STS-design methods. The main body of the summary, part 2.0 is a discussion of the thesis' research papers. I use the model of '(un)productive tensions' to highlight how various challenges became productive for making the final argument. I summarise these as propositions while going along. In part 3.0 I make the last case; Prototyping patient 2.0 as a way to draw in the main propositions (from the work on the collection of papers) and go a step further to make a coherent argument (elaborated in this extended summary).

Research questions and approach

Some of the research questions that have been guiding my research include³: *How can we, better, design useful information technologies in healthcare? How can we make ethnographic research contributions that can become generative in healthcare technology design? In what ways should we, fruitfully, involve participants in design?*

While these questions are broader in character the following are more to the point: *In what fruitful ways can ethnography and participatory design become assembled? How could we possibly integrate critical observations with suggestions or enactments of how it could be otherwise? In what ways can we design and research that, which we want to create?*

And a last: *How do you prototype something, which is a collective (a network of human and non-human actors)?*

As this thesis summary is an extended discussion of methodological issues, the way I, or what I better like to call 'we' (in line with the overall argument), have approached the research and development process is very much spelled out throughout the thesis. The method discussions are at times so detailed that I risk giving a too realistic exposure of the way I have come to agree what I do. However, in concrete terms the approach can be divided up into a prototype software development process, project management activities and design research experiments with participatory design and ethnography of working prototypes in patients' homes and hospitals.

³ The personal motivation leading to the research questions can be summarised as follows: On my master's thesis from 2007, entitled; "Hidden recourses of modernity – On standards in laboratory work", I examined how standards and standardization permeated a hospital laboratory's organization, its collaborative work practices, and apparatus. By interviews and observations of different activities in the laboratory it became very evident, that a myriad of different kinds of standards were intractably bound to the accomplishment of most activities. Generally hidden and background, standards resourced enormous potential including making it possible for only a few lab technicians to undertake the handling of more than 15.000 samples a year. As such, my work rendered important aspects of the laboratory's work analytically understandable but I was left with an unsolved challenge of thinking through how exactly these insights were constructive or could translate so as to mediate or, in whichever way, support the development of computer-based systems or artefacts. This is one of the main sources of motivation for beginning this PhD.

List of Papers

The following list of papers constitutes the main body of the thesis:

- Paper 1 Andersen, T., Bjørn, P., Kensing, F., and Moll, J. (2010). Designing for collaborative interpretation in telemonitoring: Re-introducing patients as diagnostic agents, *International Journal of Medical Informatics*.
- Paper 2 Andersen, T. (2010). The Participatory Patient. In proc. of the *Participatory Design Conference (PDC'10)*, Sydney, Australia, 2010, p. 151-154.
- Paper 3 Andersen, T., Halse, J., and Moll, J. (2011). Design Interventions as Multiple Becomings of Healthcare. In proc. of the *Nordic Design Research Conference (NORDES'11)*, Helsinki, Finland, 2011, p. 11-20
- Paper 4 Andersen, T., Moll, J., and Monsted, T. (Submitted). Practicalities of Participatory Prototyping. *CoDesign, 2013* [Special issue: Codesigning through making]
- Paper 5 Andersen, T. (Submitted): Medication Management in the Making: On Ethnography-Design Relations. In proc. of the *Computer-Supported Cooperative Work Conference (CSCW'13)*, 2013.

The following is a list of conference abstracts, workshop papers, and a business idea submission that are not included in the thesis:

Andersen, T and Kensing, F. (2009). *Standards in laboratory infrastructure - on three dimensions for design*. Infrastructures for healthcare 2009, Copenhagen, Denmark

Andersen, T., Bansler, J., Bjørn, P., Havn, E., Kensing, F., Moll, J. Mønsted, T. Schmidt, K. (2010). *Co-constructing IT and Healthcare*. Poster presented at ECSCW'09, Vienna, Austria, September 7 –11, 2009.

Andersen, T., & Monsted, T. (2009). *Rationalising Shared Care: The Case of the Referral*. Workshop paper presented at ECSCW'09, Vienna, Austria, September 7 –11, 2009.

Andersen, T. and Moll, J. (2010). *Prototyping Patient 2.0*. Paper abstract presented at EASST010, Trento, Italy, September 2, 2010 – September 4, 2010.

Andersen, T., Moll, J., Mønsted, T. (2010). *Philosophical Issues: When design meets research*. CEPHAD 2010 Conference – The borderland

between philosophy and design research. Published in 'Copenhagen Working Papers on Design' Vol. 2 2010. p. 137-139

Andersen, T., Moll, J., and Mønsted, T. (2010). *Prototyping (in) Healthcare*. Workshop facilitated at PDC'10, Sydney, Australia, November 29, 2010 – December 3, 2010.

Andersen, T. and Moll, J. (2012). *myCareLink - A Personal Health Record for ICD Patients*. A Medtronic Eureka Idea submission report p. 1-78.

PART 1.0

In this introductory section, I will present the fields of research from where this thesis begins; CSCW and participatory design. Since the general narrative of the summary is guided by the temporality of the project I will present the first case, which Troels Mønsted, Jonas Moll and I carried out; the case of the referral. I will end part 1.0 with a description of the first prototype v. 1.0 (*Diary*).

Understand, to Design

Ever since the programmable machine left its cradle and became what we call the computer, hard- and software designers have been concerned with the ‘fit’ between people and machines. The field of human-computer interaction (HCI) has upon its heritage from human factors and ergonomics advanced our understanding of the relationship between the human and the computer – ultimately, framed as a problem of the *interface*. Since the beginning of the 1980s and with the first major conference held 1982 in USA, HCI has been particularly influenced by cognitive psychology and behavioural science (Bannon, 2000). By the merits of this tradition, laboratory experiments have been applied to create (natural) scientifically valid and reliable studies of user-computer interaction. Here, it is assumed that validity of findings is guaranteed if scientific methods are used and followed properly. Therefore rationally validated methods and ‘validity’ of the matter are established *prior* to their application (Crabtree, 2003, p. 46). The effort to make these studies scientifically rigorous has although made it difficult to generalise findings from laboratory experiments to real-world contexts (Bannon, 2000; Crabtree, 2003; Grudin, 1993). Critics argue that by employing a model of truth from the natural sciences, the idea of universality and generalisability is imposed on social phenomena, where quite the opposite model of truth is foundational; truth is situated, relative to and dependent on the situation of application. In the case of the laboratory, then, the method of experiments produce knowledge in a setting that is many times far and alien to real world practices i.e. producing results that hardly applies to the lived world.

In the same vein of critique, researchers drawing on sociology and anthropology have radically reformulated the conceptualisation of the interface, as not ‘simply’ centring on the physical boundary mediating a user with the underlying computer hardware, but moreover as including the training that is often part of using a computer and the related documentation, colleagues, customer support, etc. (Grudin, 1993)⁴. Instead of designing to

⁴ For an extended argument on this critique, see Crabtree (2003) chapter 1

meet user needs on the grounds of a better mapping of the user's and the designer's 'mental model' or a better 'cognitive coupling' between the computer and the user, an orientation towards the socio-material context of human actors in organisational settings began to enter HCI.

Workplace studies: The human, the computer, and the social

This turn to the social was rooted in dissociation with the often sequential and structured models that depicted a user as generic and as individually solving tasks by interacting with the computer through a keyboard, mouse, visual display, and other input devices. What was missing in the models was simply that they ignored the fact that computers had increasingly become part of the modern workaday world. A move from human factors to understanding people as human 'actors' was part of the paradigm change in the Kuhnian sense. The uptake of a social scientific grounding, as opposed to a natural scientific, embodied an effort of transcending the engineering mentality and reformulates the challenge for design as being the sociality of users and their interdependent work practices. 'Group work' was the original conception that united a crowd of researchers who were concerned with understanding and developing technological support for smaller assemblies of co-located cooperative actors. To them, too much of importance was left out of the dominating descriptions and models of computer use.

A couple of years after the first HCI conference, in 1984, the quite awkward term 'computer-supported cooperative work' coined a research field under the similarly awkward, but now, notorious acronym; CSCW. The most influential studies that have shaped the field are commonly known as 'workplace studies', which can be seen as a re-flowering of the sociology of work that emerged in the post war Chicago school (see e.g. Becker, 1984).

Essentially, it is an analytic and theoretically conceptual agenda that unites the enterprise of workplace studies. An agenda that is "*principally concerned with the situated organization of collaborative activities, and the ways in which tools and technologies, objects and artefacts, feature in practical action and interaction in the workplace.*" (Luff et al., 2000). Studies of workplaces are typically naturalistic, ethnographic studies, of complex cooperative environments where people are considered inseparable from the situated and contingent unfolding of activities in which tools and technologies are used. This has resulted in a very large body of nuanced empirical accounts from, typically ethnomethodological ethnographies, but increasingly also analyses of work and non-work settings based on other theoretical frameworks such as symbolic interactionism, activity theory and actor-network theory (ANT). Another outcome, besides the re-specification of concepts such as 'interface', 'awareness' and 'cooperation', is the (re-)construction of analytical concepts such as *articulation work* (Bannon and Schmidt, 1989), *coordination mechanism* (Schmidt and Simone, 1996), *invisible work* (Star, Susan Leigh and Strauss, 1999) and a more recent concept; *artefactual*

multiplicity (Bjørn and Hertzum, 2011). The many studies might be related to the interests of systems design practitioners but the principal motivations behind them are, perhaps more to the point, the long term contribution to the reshaping of the ways in which we conceive everyday social actions and interactions in the workplace (Luff et al., 2000, p. 3; Schmidt, 2000).

Ethnography and design

When this is said, the question still remains; *what does workplace (ethnographic) studies offer design?* The relationship between ethnography and design has always been an intimate issue to CSCW and part of an age-old discourse. The connection can also be traced all the way back to the reasons for the divorce with the cognitivist conceptualisation of computer use in that the rationale of CSCW states that thick descriptions and analyses of cooperative work, as opposed to experimental validity, may fruitfully be used to guide analysis of the design space. Schmidt and Bannon (Schmidt and Bannon, 1992) emphasise a reorientation for social scientists to explore exactly how insights from studies of cooperative work might be applied in the design of useful CSCW systems. They argue that CSCW is basically a design oriented research area and stress, similar to the title of their paper: *‘If CSCW is to be taken seriously, the basic approach of CSCW research should not be descriptive but constructive’* (ibid., p. 11)

Although many have argued for the usefulness of understanding ‘what really goes on’ in the sociality of work when turning to design it is also generally agreed that the relationship between ethnography and design is or can be problematic (Anderson, 1994; Büscher et al., 2001; Dourish, 2006; Randall et al., 2007). Insights and analysis from field work activities can be used in a multitude of ways in design, however, many CSCW studies generally treat the relationship as a ‘gap to be bridged’ whereby turning the connection between understanding and designing into an activity of translation or communication.

With this motive, field accounts in CSCW often convey their contribution to practice as ‘implications for design’ – so as to *inform* systems design (Button, 2000; Dourish, 2006; Plowman et al., 1995; Randall et al., 2007). But, and paradoxical to the programmatic ambition of informing design better, the impact of workplace studies in the commercial world of systems developments practice is insignificant. Bannon (2000) goes so far as to say there is none; no significant traces of successful application outside research-oriented communities.

Nonetheless, exactly for this reason we, on the CITH project, wanted to challenge the unfortunate situation and push for a research project that does otherwise – a project that succeeds to break this disconnect by ethnographically studying, designing and actually implementing a working IT system. We wanted to go “full circle” as berg (1998) calls it. It was our desire to show the world that by means of ethnographic fieldwork and analysis you can

actually make innovation – something ‘out there’ that is being used. Despite the normative idea prevailing in CSCW, few studies have actually managed to show how ethnographic analysis and theoretical constructs can impact directly on the connection between analysis, design and making a marketed innovation (Bannon, 2000). Nonetheless, this was my fellow PhD colleagues (Jonas Moll and Troels Mønsted) and my ambition to experiment with this.

Whilst inspired by an ethnomethodological aim of accounting for the ‘interactional what’ (the motives and rationale behind members interdependent socio-technical work) we sat out to understand the cooperative work of referring a patient from hospital A to hospital B – (somehow naively) believing that by understanding what actually goes on we would be much better positioned to point out the problems and then ‘easily’ design relevant solutions.

The disconnect: The case of the referral

Since the project started mid-2008, the project group had up until Christmas 2008 carried out initial fieldwork activities and produced a series of working papers covering “the patient’s home”, “IT systems at the Heart Centre”, “ICD implantation” and “Device follow-ups”. In the early months of 2009, Jonas, Troels, and I decided to focus activities to a limited area of the large network of institutions, health professionals and ICD patients. We carried out a range of internal workshops and by affinity mapping we created suggestions for relevant design themes. The mapping was based on our experiences from early meetings and fieldwork visits in patients’ homes, the Copenhagen University Hospital’s Heart Centre and collaborating local hospitals. We used the following resources to make the map: the project grant-application (description), the working papers, which describe involved actors, their work tasks, organisation, related physical surroundings, the use of artefacts/technologies, and implications for design.

The outcome of the workshops was six A2 posters with post-it notes, each divided in three columns of design research; *theme*, *focus*, and *questions*. In total, they represented themes that connected analytic foci and design potential for the organisationally distributed treatment of ICD patients in the Copenhagen region. The categorisation into theme, focus, and questions was no coincidence; quite on the contrary, it reflected the project’s ambition of researching and designing “*for improved communication and cooperation within heterogeneous and distributed work*”. To a large extent, the project accentuates similar dual objectives as we were (trying to) perform; the aim of addressing socio-technical problems of shared care by research and design of IT support for communication across institutional and professional boundaries. On the one hand, collaboration and especially distributed collaboration is the conceptual cornerstone of CSCW and on the other hand, the lack of continuity

and coordination of care is considered as one of the greatest challenges facing the Danish healthcare system by care providers and national health authorities.

Hence, the premise of the project – and now, the A2 posters and post-its gave us a good incentive to select the theme that could support this dual aim of research and design. Adhering to our attentiveness to the socio-technical in design research, the projects' premise of focusing on distributed cooperation, and aided by the ANT slogan "follow the actors themselves" (Latour, 2005, p. 12) we decided to spend the first action-research cycle on examining the case of the *referral*.

As we discussed on the workshop, we chose to study referrals because they proved to be crucial artefacts, 'boundary objects' (Star, S.L. and Griesemer, 1989), which support alignment of treatment by articulation of initial communication between hospitals. We engaged in 'infrastructural inversion' (Bowker and Star, 2000) and followed paper artefacts of referrals from their inception at the local hospital where cardiologists dictate reasons for referring using a tape recorder followed by secretaries listening, creating and mailing them – through to the University Hospital where a secretary use referrals to manage bed occupancy at the bed ward, cardiologists' use them to plan implantation of ICDs, and nurses to prepare for their first encounter with the patient. Images and transcribed audio and video recordings enabled us to iteratively draw a large (A1) flow diagram and thereby visualize the movement and transformation of referrals and their diverse usage by various healthcare actors. We presented our findings and selected design proposals to the rest of the project group in June 2009 and to a workshop audience on healthcare infrastructures at the European CSCW conference in 2009.

Consequently, we understood what referrals do; how they are created, transformed and which work practices they support and relate to. We understood reasons for breakdowns and deviances in processes and how important it was that referrals were paper-based, minimally standardised and flexible in their workings. Most importantly, we came to know how they co-construct meaningful healthcare. As I shall elaborate below, we came to know too much.

In the study of the referral our aim was, similar to many studies in CSCW, to first understand and analyse and then move into design, making design an activity that separately follows and is not integrated with the ethnographic work. Then, when moving into design – to actually employ our experiences and the ethnographic work we have carried out, we discussed various solutions to the general problems we found a common theme of those solutions included some sort of automation of activities as a consequence of wanting to enable delegation of routine work to technology (Latour, 1992). We quickly realised that automation could rarely go without standardisation which,

in many ways, became a problem for moving into design (see also Winthereik and Vikkelso, 2005). This left us in some kind of a dilemma (Grudin and Grinter, 1994 calls this the 'ethnographer's dilemma') since we knew all about the advantages of the current flexible and malleable paper based referrals afford. And, perhaps most importantly, information technology as we begin to see it would rationalise and somehow pollute the meaning inherent in the existing infrastructure. Standardising the referral would in turn mean standardising workflows, which would disrupt the very meaningful and, to some extent, very well functioning infrastructure of referring a patient. Moreover, we found it uninteresting to academic discourses to explore and experiment with a process of standardisation – there are plenty of such projects happening already within the Danish healthcare system and it would be smarter to study those than engage yet another standardisation project in healthcare.

Another problem, perhaps even the biggest, was that our (few) design ideas were sketches or *visions* of a radically redesigned technology-supported way of refereeing patients. They included all the different actors and all the different sites and envisioned solutions that involved mobile technologies and large interactive displays. This was therefore fully undoable in terms of the project resources and time to implement it. The job of translating ethnographic insights into innovative solutions did not happen. In conclusion (and in part, frustration), we discarded the idea of continuing trying to design and possibly develop solutions to transform the way hospitals refer patients. We did not succeed to go full circle. But, as many others, we succeed to carry out, and write up a classic CSCW study of some part of an inter-institutional healthcare infrastructure. And, as I will describe below, this is one of the main reasons for why we decided to change research strategy towards a process that eventually would involve design-in-use.

Design, to understand

On a two-day project seminar in April 2009 in a conference centre just north of Copenhagen, Troels, Jonas and I presented our ethnography on the infrastructure of the referral and our designed visions. The CITH project group met to share insights from fieldwork studies and to decide on the scope of the project's next stage. We decided to work on narrowing down, and to focus studies towards designs that could eventually be implemented. To make the project more agile it was divided in to two sub-groups; one group aiming to understand and design for the inter-institutional communication among health professionals⁵ and the other group focusing on patients' practices in relation to the health professionals'. I took part in the patient-centred group together with Mie Christa Jensen Larsen (project nurse), Finn Kensing (project manager) and Jonas Moll (PhD fellow). In accordance with the project's research program and as a response to our unsuccessful bridging of ethnography to design, we decided to initiate activities of more participative nature. This, we hoped might help us making the move from understanding what the current problems are to design and development of something useful for the patients and the clinicians.

Soon after the seminar and as part of changing our approach towards activities that included design as part of developing an understanding (mutual learning), we planned for what became important moves towards a transition in design research activities. That is, activities that eventually would make it possible to move away from the conventional problem-solving i.e. 'understand, to design' towards 'design, to understand'.

Important activities that helped this transition include:

- Structuring design research activities into 'action-cycles'
- Running a 'situation-card workshop' with patients
- Creating a collaborative document, 'design concepts'
- Hiring a part-time prototype web-developer
- Sampling patients (identifying, contacting and enrolling)
- Deciding to prototype a patient-centric web application

Convinced, that participatory design would enable a more fruitful strategy of getting to understand, design and implement a technological solution, we looked to action research for a way of managing the production of analysis and design. The fundamental idea behind the combination of action and research is to pair the ambition of making relevant change while contributing to knowledge production in related research communities. This, we believed, would allow us to keep our 'ethnographic curiosity' of understanding what

⁵ The group members were Jørgen Bansler, Pernille Bjørn, Erling Havn, Troels Mønsted and Kjeld Schmidt.

actually goes on in patient and healthcare practices while designing meaningful IT solutions and propagating (positive) change. Two influential versions of action research that are widely applied in the field of information systems, are Checkland and Holwell's (1998) and Baskerville and Wood-Harper's (1996) versions. They propose a step-wise, cyclic and iterative action research process where (idealised) 'action-cycles' move sequentially between joint activities of reflecting, planning, intervening, and evaluating. The authors' versions of action research both suggest that issues of validity need to be dealt with by e.g. explicitly stating what the experienced problems are, what will be changed, what the choice of theoretical framework is and which method will be applied. In this way 'recoverability' meaning 'declared-in-advance methodology' is applied. However, for a start, we did not find our process ready to undertake such structured action cycles and instead we began only to prepare for a 'true' action cycle by grouping the first set of activities into a 'cycle' and think in terms of how to combine reflection, planning, intervening, and evaluating.

As a first activity of moving the project into a more action oriented, participatory design process we invited two patients whom we had already visited in their homes and two patients whom we met at the Heart Centre after a patient information meeting. We wanted to qualify our early findings from our field visits and engage the patients in discussions and envisioning solutions to challenges they experience. Inspired by the highly developed application of design games in participatory design (see e.g. Brandt, 2006) we translated our main findings into situations and grouped them into themes. We made a game board and 20 game cards with question-prompts that were related to text of elaborated situations that we believed most of the patients would be familiar with⁶. We learned many things on the workshop such as how important relatives are in relation to managing illness, the much work and many actors involved in medication management (see paper 5) and that heart-treatment is highly specialised and is governed by local hospitals and the Heart Centre – and not the general practitioner. Nonetheless, in the end we found that we (yet again) actually did not spend enough time discussing solutions because, in general, the four patients were rather positive towards the treatment and health care they received and were not overly keen on discussing how it could be otherwise envisioned.

On the other hand, this did not hold us, design researchers, from having ideas and intense discussions on how the patients' everyday management of their illness including communication with health professionals could be

⁶ Examples of *situation card themes*: "Communication with health professionals", "rehabilitation" and "medication". Example of *situation elaboration*: "You are in a consultation at your local hospital, the doctor asks you how you've been since the last visit". Examples of *question-prompts*: "How have you prepared for the consultation? Have there been any problems since the last consultation? Do you find that the doctor has a complete overview of you / your total diagnoses?"

supported. To maintain and develop these ideas we created a collaborative document describing and listing possible design concepts. We motivated each design concept with insights from patient situations and expanded (in bullet points) experienced problems and solutions as well as implications for design⁷. As from Finn's participation on similar earlier research and development projects (see Bansler, J. P. and Havn, 2010; Winthereik, B. R., 2010; Winthereik, B. R. L., Henriette, 2010) and by considering his dialogue with stakeholders at the Heart Centre, we realised that many of the design concepts could be supported by a patient's *own* online medical record. Typically, cooperative systems in healthcare are created to support professional communication. For some reason, most probably of economic and reasons of technological maturity, chronic heart patients in Denmark only have few online tools available that are integrated with the clinic⁸.

So, we slowly decided to begin prototyping a patient-centric web platform⁹; a web application that patients could use for something. This 'something' we needed the participants to help us develop, but then again, we had some ideas already. To gain momentum, the strategy, then, was to mix those ideas with interests and wants of the coming participants. But, and this is important for the thesis as a whole; we were still keen on integrating a critical analytical ethnographic approach with the participatory design of a patient-centric platform, because we believed that this could be potentially innovative. Either way, for this to happen needed a dedicated web developer to implement the designs and sketches we would make. To enable this we began a hiring process looking for two prototype web-developers. The reason why I include the trivial act of engaging a hiring process, making a job advertisement poster, and hanging it in various places such as at the IT University of Copenhagen, is that we would have not succeed to get acquainted with Anselm Christophersen, a talented web developer, had we not taken the hiring process serious. That is, we would have not been able to make the method experiments and the arguments that I make with this thesis. This poster therefore signifies our serious aim of changing strategy to what would become design *and use* of a

⁷ Example of design *concepts*: "Systematized and continual recording of events", "Personalized and automated feedback on ICD-transmissions", "Dialogue Support - enhancement of dialogue between patient and health professionals" and "Patients empowerment". Example of *motivation* to the design concept "Systematized and continual recording of events": "It appears from our studies that there is a need to support patients to detect and classify events that patients experience in their lives when they are not in contact with health professionals". Example of *problems*: "Patients forget to report on significant experienced events", "Unclassified questions create uncertainty and make patients feel insecure", "Patient articulated anamneses are not exploited" and "Systematized patient experiences are not exploited as basis for research". Example of *solutions*: "Diary-based event recording", "Write down issues", "Categorize records", "View and print records" and "Overall summary of records".

⁸ There is although a working infrastructure (healthcare devices, telephones, information paper forms, email etc.) connecting patients and clinicians (see Langstrup et al., 2010).

⁹ We discussed the advantages of other platforms that are more accessible, such as the TV and digital-pen and paper.

working prototype. At the end of the summer 2009, four months later, Anselm was ready to start development, and all the grounds have been mobilised to begin a process of participatory prototyping.

Now that we had changed the overall research and development strategy from doing a classic CSCW study (first ethnographic analysis, then design) to doing participatory design – I it is necessary to present and position our approach to cooperative prototyping within the field of participatory design. Below, I will therefore do what I did above with CSCW, and introduce the main currents shaping what is today known as the research field of participatory design.

Participatory Design

Participatory Design is, similar to the field of human-computer interaction, rooted in post-war industrial movements. Instead of being founded on the spatio-technical and cognitive and bodily properties of humans (human factors), Participatory Design is founded on a socio-political and organisational interest in quality of working life and job enrichment. There are many influences and political movements that have led to the shaping of participatory design (see Bansler, J., 1987, 1989; Kensing, Finn and Greenbaum, 2012). Some originate in the 1960s Tavistock socio-technical school in Britain where the overall goal was organisational change with the dual objective of increased job satisfaction and work efficiency¹⁰. In many ways it was a response to the capitalist rationale inherent in the Tayloristic way of organising work (i.e. scientific management). The focus of the socio-technical school, was not on the individual alone but on the individual as part of a group in an organisation whereas the idea of participation becomes fundamental to the socio-technical design philosophy. It was researchers at the Manchester Business School, and in particular Enid Mumford, that took the socio-technical analysis to systems design (Ehn, P. and Kyng, 1987, pp. 24-25). In their book ‘A participative approach to computer systems design’, Mumford and Henshall (1979) describes the socio-technical approach to systems design by a case study as:

“an attempt to use the introduction of a computer system as a catalyst to improve the quality of working life through giving a group of white-collar employees responsibility for designing their own work organization. It therefore uses the introduction of new forms or levels of technology as a vehicle for employee participation and job design. The computer is an excellent catalyst as it is not a deterministic kind of technology.”
(Mumford and Henshall, 1979, p. 2).

¹⁰ This line of thinking also became present in British politics in the 1970s where it was widely agreed that democracy should be extended throughout industry by means of employee participation.

During the seventies Kristen Nygaard, Åke Sandberg, Bo Göranson, and Lars Mathiassen (all researchers) were some of the more influential ones who imported this approach to Norway, Sweden, and Denmark. They were, although, critical to the socio-technical approach since they found strategic shortcomings in the practical applications. As a consequence they developed the ‘Collective Resource Approach’ “to formulate a research approach for democratisation of systems design” (Ehn, P. and Kyng, 1987, p. 25) and argued for (and practiced) a strong local union involvement. The first Scandinavian union project was the Norwegian Iron and Metal Workers Union (NJMF) in 1970 followed by the DEMOS¹¹ project in Sweden in 1975 and the Danish DUE¹² project in 1977¹³. In ‘second generation’ projects such as the UTOPIA project¹⁴ the idea of actually *designing* new technology as “tools for skilled work” was introduced to complement “democratic planning” (Ehn, P. and Kyng, 1991). Research projects were formed in cooperation between the union, employees and research institutions “to *try* out the ideas in practice” (ibid., p. 32) – the aim was double; to design computer support and professional education. In this way, use and design are integrated as opposed to more traditional and formalistic systems design methods where requirements are “frozen” and thus separated from use. The Utopia project and many similar projects became known as the Scandinavian Tradition of Participatory Design. In this work the researchers formulated several theses based on their experiences on design of new technology including:

- “*Design of computer support is design of (conditions for) labour processes*
- *Important aspects of labour processes – in relation to design of computer support – cannot be formally described*
- *Design should be done with users, neither for nor by them*
- *[M]utual learning should be an important part of the work in a design group*
- *Design by doing [to simulate by building mock-ups]”* (Ehn, P. and Kyng, 1987).

The Scandinavian approach to systems design thus rejects what is fundamental to the rationalistic tradition where individuals in isolation treat specific work tasks as formalised data processing carried out. Similar to workplace studies and CSCW, participatory design builds on what I have described above as a turn to the social where people at work are considered part of a broader context of *situated actions* (as opposed to being guided by

¹¹ DEMOS is short for “democratic control and planning in working life: On computers, trade unions, and industrial democracy”. In Swedish: “Demokratisk styring och planering”

¹² DUE is short for “democracy, education, and computer-based systems”. In Danish: “Demokrati, udvikling og EDB”.

¹³ For extended details from these and later Scandinavian union projects see e.g. Bansler (1987), Bjercknes, Ehn and Kyng (1987) and Ehn (1993).

¹⁴ See Bødker et al. (1987) and Ehn and Kyng (1991) for case studies from the UTOPIA project

concrete plans) (Suchman, L. A., 1987) that involves complex social relations. Cooperation with the worker/user is fundamental to participatory design not only because of its heritage from the socio-technical school (politically democratic aim) and the aim of workplace studies (understanding what actually takes place at work) but moreover to strategically engage in situations of mutual learning whereby overcoming the knowledge barrier between workers and systems designers. Workers skills are centre of attention and by active cooperation between practitioners and systems developers, tacit dimensions of work gets articulated and future use situations are envisioned.

The inclusion of a temporal dimension in the design process that of imagining the future and cooperatively transforming this imagination into computer systems and work practices are moreover a particular feature of the cooperative design approach. This is why *simulating situations of use* are important to methods and techniques in participatory design. Introducing mock-ups or simply discussing alternatives while situated in the accomplishment of some work task, transcending it is not only envisioned, but also tried out as part of the existing practices. The term ‘computer system’ is considered both the entity itself and the way it is used. Design, development and use are in many participatory design methods happening simultaneously as on-going creative activities. As an alternative to treating the problem of systems design as one of trying to device a set of clear defined problems and then searching for one “right” solution, participatory design approaches the conditions of developing computer systems for the workplace as dynamic and generally messy (Greenbaum and Kyng, 1991). This entails a strategic focus on *process* where the interactive character of development and use is stressed to overcome the view of systems as static structures. “Design by doing” is emphasised as a pragmatic and particularly action oriented approach that highlights the focus on “doing” work cooperatively with users over developing formal descriptions (Greenbaum and Kyng, 1991). Fundamental to the participatory design research program is “*creating new ways of working together [users and system designers]*” (*ibid.*). Nonetheless, participatory design has developed in many ways and the discourse on devising and applying (new) methods, tools and techniques to support the political, ethical, or simply the participants’ interest, has grown since the first conference.

Participatory Design is an eclectic research field that builds on thinking from e.g. feminist studies, American pragmatism (John Dewey’s work on ‘active learning’ and ‘experience’), Donald Schön’s (1983) reflective practicum (problems are made intelligible only through attempts at solving them) and workplace studies (anthropology and sociology). Social sciences and humanities are grounding most participatory design research contributions and the epistemological base originates in *social constructionism*. In Greenbaum and Kyng’s (1991, p. 12) terms (editors of the much cited classic participatory design book “Design at Work”) social constructivist theory “steers toward

understanding different, pluralistic perspectives of how we think and act” and “sees our understanding of the world as generated by people (through their social interactions) rather than as a set of fixed, immutable facts”. Nonetheless, design as methods, tools and techniques, are put centre stage as a pragmatic response to the cooperative making of remodelled work practices. Hence, an overly different approach than the one of most CSCW contributions where activities are reversed such that understanding of practice is favoured and precedes activities of design – i.e. *understand, to design*. In participatory design, understanding users is considered a pragmatic challenge where ‘designing’ is the overarching approach for mutual learning i.e. *design, to understand*.

The direction of participatory design which my work is particularly inspired by, includes Bødker, Kensing, and Simonsen’s (2004) innovative methods, tools, and techniques to technology and systems design wherein organisational and business strategic alignment is considered practically important (For an elaborate introduction, see Kensing, F., 2003).

Cooperative prototyping

Prototyping is an inherent part of participatory design and have been practiced as early as 1978 (Mumford and Henshall, 1979) and by the Collective Resource Approach it was introduced to the Scandinavian Tradition of participatory design (Ehn, P. and Kyng, 1987). The concept of prototyping typically covers a wide range of definitions and approaches – from early paper-based mock-ups (Ehn, P. and Kyng, 1991) to the iterative, in-situ co-design and simulation of use by envisionment (Bødker, S and Grønæk, 1991a) and have been applied in multiple ways. In the proceedings of the Participatory Design Conference in 2010, 11 out of the total 15 full papers reported the use of some version of “prototyping”.

Traditionally though, prototypes have predominantly been applied to either explore, clarify requirements, or evaluate a proposed solution (Floyd, 1984). Common to some early approaches are that the prototype was (only) made to *represent* use and user requirements in different ways and therefore not applied as a method for co-design with potential users. In systems development in the late 1970s, prototyping although emerged as a reaction against more rational and at traditional phase-oriented models such as the waterfall model. The general critique comes from the same influences of participatory design; the problem of requirements ‘frozen’ in documents, having successive well defined stages of development, detached analysis and so on. The general philosophy of prototyping is to iteratively and pragmatically develop (partial) solutions and thereby construct the future. It works by an integration of analysing current practices and designing new ones (Mogensen, 1992). Instead of primarily being a tool applied to *communicate* designs, prototyping in participatory design has been developed as a means to facilitate participation and design. It is used to effect alignment between the multiple

interests and thus, to practically support discussion and articulation of problems in current work practice and goals for future ones. Prototypes are “*at once intelligibly familiar to the actors involved and recognizably new*” (Suchman, L. et al., 2002).

Bødker and Grønbæk (Bødker, S and Grønbæk, 1991a, 1991b) suggest “Cooperative Prototyping” as an approach to participatory design where they take a step further and move prototyping in to situations where use can be simulated. This simulated future work situation they call “envisionment”. Envisionment is employed to obtain a close coupling between design activities and experimental evaluation of prototypes in what they call “work-like situations” (Bødker, S and Grønbæk, 1991b, p. 198):

“To experience is not to read a description of the computer application, nor is it to watch a demonstration. We have found prototyping to be very useful in uncovering unarticulated aspects of users' work and in having them contribute to the design of improved tools. In envisionment, breakdowns may lead to a change in the prototype, and eventually to a change in the future computer application. What we find useful in prototyping, relative to the use of mock-ups as described in Chapter 9, is that a prototype better shows dynamic aspects of the future application.”

As such, prototypes are tightly incorporated into all aspects of the participatory design process and works to facilitate a range of practical challenges inherent in moving from current situation to suggested new ones.

Suchman, Trigg and Blomberg (1996; 2002) take it a step further and employ prototypes in actual situations of use. By prototyping they engage in “design-in-use” but they also include an ethnographic interest and let situations, along with the prototype, become means by which they undertake ethnomethodological studies. It is by combining “work practice studies” and “design interventions” that the prototype becomes valuable. Similar application is present in later work by Halse, Binder, and others (Binder, Thomas et al., 2011; Halse, 2008; Halse et al., 2010) including the work carried out as part of this thesis (paper 3) (Andersen et al., 2011). As this is part of the points being made in the sections below, I will return to the issue of combining ethnography and participatory prototyping throughout part 2.0 and part 3.0. However, what might benefit the reader at this point is to hint that exactly the idea of prototyping to facilitate simulation or ‘envisionment’ is rather different than actually employing prototypes in the re-design of them as part of use-time. This will be made clearer below.

www.diary.cith.dk [Prototype v. 1.0]

Now, leaving the short review of Participatory Design, the second main influence in my work, I will continue from where we left the project. As we had turned to participatory design and prototyping, we decided to aim at

“getting something out” as soon as possible. In the first iteration, which called ‘action cycle; Prototyping I’, we worked hard to pursue the aim of converting the design concepts into a working prototype that could become a vehicle for a participative and dynamic process of design and use and ethnographic research. The aim was not only a pragmatic choice to engage a participatory design process but moreover a research strategic choice to make it possible to combine ethnographic curiosity with design by doing. It was a first step of setting up a series of design research experiments.

Ever since the summer seminar where the CITH project team I was part of decided to begin prototyping a web-based patient-centric application, we wrestled with managing and translating heterogeneous inputs and a growing amount of empirical data into sketches of a web application. Now that the technology was decided – a web platform developed upon an open source content management system (CMS), we had made clear boundaries as of what possibilities in terms of design feature, we could implement. We worked intensely drawing in multiple and heterogeneous sources of empirical data in sketching the first version. It was, although, not before an internal design session in late October 2009 that we had a breakthrough of sketching something that we felt could hold the most relevant features for a first version of the prototype. With ‘relevant features’, we meant potentially relevant for patients and health professionals but also potentially relevant as a tool for probing and supporting ethnographic inquiry into patient practices.

The first version of the prototype was therefore packed with many interests and questions (similar as the subsequent versions). To some extent we employed the first version very much open-ended with a mix of pushing for uncertainty and getting concrete information from patients. In some ways the first version came to work as a probe (Gaver, B. et al., 1999; Mattelmäki, Tuuli, 2005) while also being a kind of diary study, known as elicitation studies (discussing patient generated empirical data) (Carter and Mankoff, 2005). In this way, we believed it could potentially become relevant for the participating patients who might use it, as well as relevant for us as design researchers making design research experiments.

We named the first prototype *Diary* to indicate the duality of its purpose. For global access it was accessible from www.diary.cith.dk and besides the entry webpage, a user login webpage, users (patients and their relatives) were presented with the Diary homepage where most of the page’s real estate was taken up by three big clickable buttons: (1) Experience, (2) Dialogue and (3) Summary.

The Experience-webpage was designed as a conventional online diary with a title and a description text input field. In addition it had a health related input area with fields to record morning weight, blood pressure and pulse and

it had checkboxes¹⁵ to indicate e.g. lack of breath, abnormal heartbeats, dizziness and faints as well as possibilities to create individual categories. The title ‘Experience’ (‘oplevelse’ in Danish) also worked to let it be up to the users’ own interpretation for use i.e. recording health related experiences as well as other perhaps social or otherwise private experiences. With a title and description entry field, the Dialogue-webpage was similarly dual in purpose; on the one hand it was a diary tool for patients to keep track of the many engagements they have with health professionals while on the other hand it was an invitation to let patients write, to help us understand their movements in the healthcare system and the reasons for it. A helping text on the Dialogue-webpage says: *“Please note who you have talked with, about what and why. Also note your upcoming meetings with health professionals”*.



Screenshot of the first prototype v. 1.2, *Diary*

The Summary-webpage was designed with three text input fields (title, summary and questions) to let patients prepare for consultations and other meetings related to their treatment while providing us as design researchers with the possibility to study how consultations would be with patients’ summaries of the period in-between meetings: “Please write a summary and questions you would like to pose at your next meeting with a health professional”.

¹⁵ The checkbox selection options were initially suggested by a cardiologist and later refined by cardiologists at other hospitals. We used to talk about the options as answers to “the ten most important questions” in consultations with heart patients that have an ICD.

Diary, the first prototype, was released in two versions on two 'launch workshops', one month apart (so were the following versions, two and three). On launch workshops, which I shall describe below, we invited the participating patients and their relatives to come along and see and hear about their new tool. They were released in October and November 2009 with a total of twelve patients provided with user name and password.

PART 2.0

It was winter in Copenhagen and the beginning of a new year; January 2010. The two groups of participating patients, all users or non-users of the prototype version 1.0 and 1.1 ('Diary') have had access to use it for more than a month. The participating health professionals could not access Diary online and it was therefore only the patients that could use it¹⁶. Jonas and I met at the University (of Copenhagen) to begin planning for another phase of the project with focus on engaging participatory design activities and keeping project momentum. We reviewed patient entries in Diary and discussed how we could get better at translating empirical findings into features of the next version of the prototype. We also discussed which main features would be possible to implement and suited for the upcoming design research experiments. That is, features that would support being a useful tool for the participants and a useful tool for making design research experiments. In the following two weeks, we held a range of internal design research sessions and project management meetings where we began drawing the broad lines of what features a version 2.0 and 2.1 of the prototype could look like. We discussed technical possibilities with the web developer and began planning for upcoming design research activities. The core activities developed and carried out the second phase of prototyping the patient-centred web application can be grouped and listed as follows:

- Internal design research sessions and project management meetings
- Co-design sessions with patients (one/two participants)¹⁷
- Co-design workshops with health professionals and patients (multiple participants)
- Launch workshops of the prototypes
- Design interventions in patient homes, the Heart Centre and local hospitals
- Practicalities of actualising (all the points above).

After we changed our approach to doing participatory design and cooperative prototyping, the project undertook immediate progress in regards to design and development of the web application. This motion increased our confidence in the project and provided a space for challenging our methodological approach of experimenting with ethnography and participatory

¹⁶ Because of security reasons, it was not possible to navigate to www.inform.cith.dk using computers at the hospitals. Negotiating online access for the health professionals therefore turned out to be an organizational challenge. We had to locate IT administrators, initiate a request, get consent from the right persons etc. which in the end made us drop it and instead make a practical workaround: to show printed screen shots of the prototype, such as patient recordings.

¹⁷ We did this as a way to elicit and discuss the patients' experiences with use (in situ), why and what they have written and what should be re-designed.

design. On the one hand we wanted to continue expanding our reflexive attention to design activities because it made the project much more dynamic. On the other hand we still assumed that integrating ethnographic inquiry into the process would be beneficial for both design and research. This was primarily because it was (still) our belief that the better we understood the participants' practices the better we would be able to design something useful. Additionally it was because we believed the setup of the project would enable us to produce interesting discursive contributions.

However, and perhaps the most important ambition in relation to this thesis, we were determined to explore and experiment with connections between methods, which traditionally are synonymous to ethnographic work, and methods, which traditionally are synonymous to designerly action. In our design research sessions and project management meetings we discussed this subject intensely through questioning similar to: *In what ways is the prototype an instrument relevant for the patients as well as an instrument relevant for making their (future) practices describable? And, is a design session in a patient home primarily a design activity or could it also be an activity of creating empirical data for an ethnography on the making of patient empowerment?*

Another example of questioning that we struggled with was: *If all the work of making a website, flyers and explanatory videos and if calling, emailing and sending letters is necessary to make patients and health professionals interested – is it not, then, conditional for the both research and design to succeed? And, why is all this 'other' work, the mundane practicalities, seldom discussed in the CSCW or participatory design literature?* In sum, we had engaged a process where tensions between ontological and epistemological questions were not only actualised as part of our design research activities but beginning to become present in post-analytical work. In fact, this interdisciplinary application of method pushed for continual reflexivity and demanded increased attention towards which moves to take and how to reason in every situation. This, in turn, led to numerous discussions and wondering which, at the time, felt as extreme overhead work and as tensions that were rather unproductive for the participatory design of the prototype. These unproductive tensions that later proved productive for research, is what I use to structure the sections below.

The line of questioning, that I brought with me from the work on my master's thesis (workplace study on standards in a hospital laboratory), included: *In what ways can analytical concepts and ethnographic insights become generative in design?* In the beginning of the CITH project I was for example interested in the concept of *patient empowerment* and what it could *do* when designing healthcare IT. In a similar way I was inspired by Unruh and Pratt's (2008) conceptualisation of 'the invisible work of being a patient' and thinking how it could become constructive in our participatory design engagements. Later I became intrigued by Marc Berg's (1997) analytical frame of 'rationalising

medical work’ and it interested me, what it could do when subjecting our first prototype to analytical scrutiny and as a resource for methodological reflections on our design research approach. Later into the project, the Oudshoorn’s (2008) concept of patients as *diagnostic agents*, *inclusion work* and *non-use* (Oudshoorn, N. and Pinch, 2003) in relation to information technology in healthcare, caught my attention. Patient *homework* (Grøn et al., 2008) and the emergent concept of *patient 2.0* became devices for analytical reflection, and as I shall describe below, devices generative and performative in design research action.

With these types of questions, we began to formulate it as a concern for the relationship between research (ethnographic work) and participatory design— sometimes understood as each other’s opposite, yet at other times as impossible to separate in practice and in post-analytical discussions. We quickly realised that the fields of research from where we departed (CSCW and Participatory Design) did not offer the vocabulary and the philosophical reflections that we were trying to articulate. In our search for scholarly work on this matter we found that the broad field of *design research*, in its eclectic and particularly inter-disciplinary body of literature, was engaged exactly in the articulation of such philosophical discourses. Especially the methodological term ‘research-through-design’ was inspiring. However, before I engage a discussion of these matters I need to introduce the design research activities and the design of the second version of the prototype.

www.inform.cith.dk [Prototype v. 2.0]

Engaging participatory design activities with working prototypes in use intensified the work of managing participants and other stakeholders, coordinating interests, and informing participants. It demanded increased, continuous attention to practicalities of organising the project (which I will develop below) and introduced increased complexity. But at the same time it opened up for an excess of possibilities, especially possibilities of experimenting with method. Before I introduce the papers of the thesis and the outcome of what I call (un)productive tensions, I will present the different types of activities we engaged in. That is, the design research activities listed in the beginning of the chapter. These six types of activities have been grounding the design research work throughout the project, whereas the following are examples only from activities of making the first and second version of the prototype. The insights presented are all translated and embodied in the prototypes. I have included the activity descriptions in some detail as a way to stress three things:

- Firstly, that a large body of work in making this thesis resides in the practical accomplishment of the undertaking of the many design research activities (including the agile software development process of making the prototypes).
- Secondly, the six versions of the prototypes, which emerge from the following types of activities, actually carry a plethora of stories that only appear as described a few places. The prototypes themselves are technical-material contributions that are part of this thesis.
- Thirdly, to illustrate how rich ethnography, when practiced as participatory design activities, potentially is.

Co-design sessions with patients

To get started with the second phase we planned and carried out two co-design sessions at university with patients who had been using the first version of the prototype. We used these sessions to get feedback on their initial thoughts of using prototype v. 1.0. We engaged the text they had written in the prototype as prompts for discussing v. 2.0 design concepts. In this way, the early field trips and interviews we carried out in patient homes had changed to include a working prototype.

These sessions targeted experiences of (past) use and collaborative design of the next version of the prototype. The co-design sessions were a step away from doing classic ethnographic field studies with the primary goal of understanding patients' practises and a step towards a merge of understanding while designing patient practices *equipped with the prototype*. We asked questions

such as: *What is your experience using the prototype? What has worked and what has not worked? And what are the strengths and weaknesses?*

From the first couple of co-design sessions we learned several things. One patient said that it has been helpful to be able write down symptom experiences or other worries – *“to get rid of all your concerns”, “to be able to return to the history of entries”* and *“to be able to present what my current health status is to health professionals”* (Transcription of audio, January 2010). We asked why he had frequently been entering INR blood test results in his diary in the prototype and he explained that these numbers *“to keep myself informed on the dose of Marevan [anticoagulant medication] and the levels are what the doctor acts upon”*. He had also written his online communication with his general practitioner using cure4you.dk [general practitioner-patient communication platform] and written his own version of his medical history. He had entered his medication list in details and a “lab result from a blood test that cannot be added here – wherefore I’m transcribing” (indirectly suggesting a place to store lab results).

At that time we did not get around the reasons for why he chose to enter all these types of information but it proved valuable inspiration for design activities. Especially, sharing the list of medication was an early ‘seed’ in the sketching of features for the next version. In the other co-design session in a patient’s home we discussed the need for an area in the prototype to enter/view basic data such as date of birth, blood type, ICD device type, and implant date. It might, as he said, become useful information for the clinicians. To *share information* with clinicians turned out to become a central topic in the development of v. 2.0. Similar to discussions in the previous co-design session he had also been writing down questions in relation to his medicine: *“What is the connection between the drug Cozqaar, which I get 50 mg. of daily and my days with dizziness?”* He had noted symptoms: *“Days with dizziness and low blood pressure”*, and blood pressure values several times e.g.: *“110-120 over 65-70”* and written: *“I will in the future measure my blood pressure regularly to see if there are large differences in the values”*.

He told us what he carries at all times; a “PM/ICD card” that has his name and contact details on the implant-centre (the Heart Centre) and device data; a Medtronic research study card indicating he is taking part in a research project; a paper-slip indicating the date he started “anticoagulant therapy”, and a “Follow-up card” from the Heart Centre with nine lines to manually fill in day, date and time for up-coming follow-ups. The other patient had shown us his European Pacemaker Patient Identification Card, which he carries in his wallet. Again, all these different very physical and tangible pieces of information-communication devices participated in informing us on what data is important to share.



Collage of pictures from (the practicalities of) co-design sessions and workshops

Regarding his use of first version of the prototype, he explained that it encourages “*continual use*”, which sometimes contradict with periods where you feel well and do not want be reminded of your disease. He also emphasised that “*knowing that there are someone reading and able to give feedback*” would be a major benefit of the system – the prototype incites “*dialogue*”. Nonetheless, he explained that there are some major changes in information needs, which follow the “*phase*” you are in (acute and stabile). We also talked about how he was looking for patients like he to get answers to questions and advises – especially in the time just before and after implantation. In a kind of a forum “*you could make yourself available to others like ‘you are welcome to call me’*”.

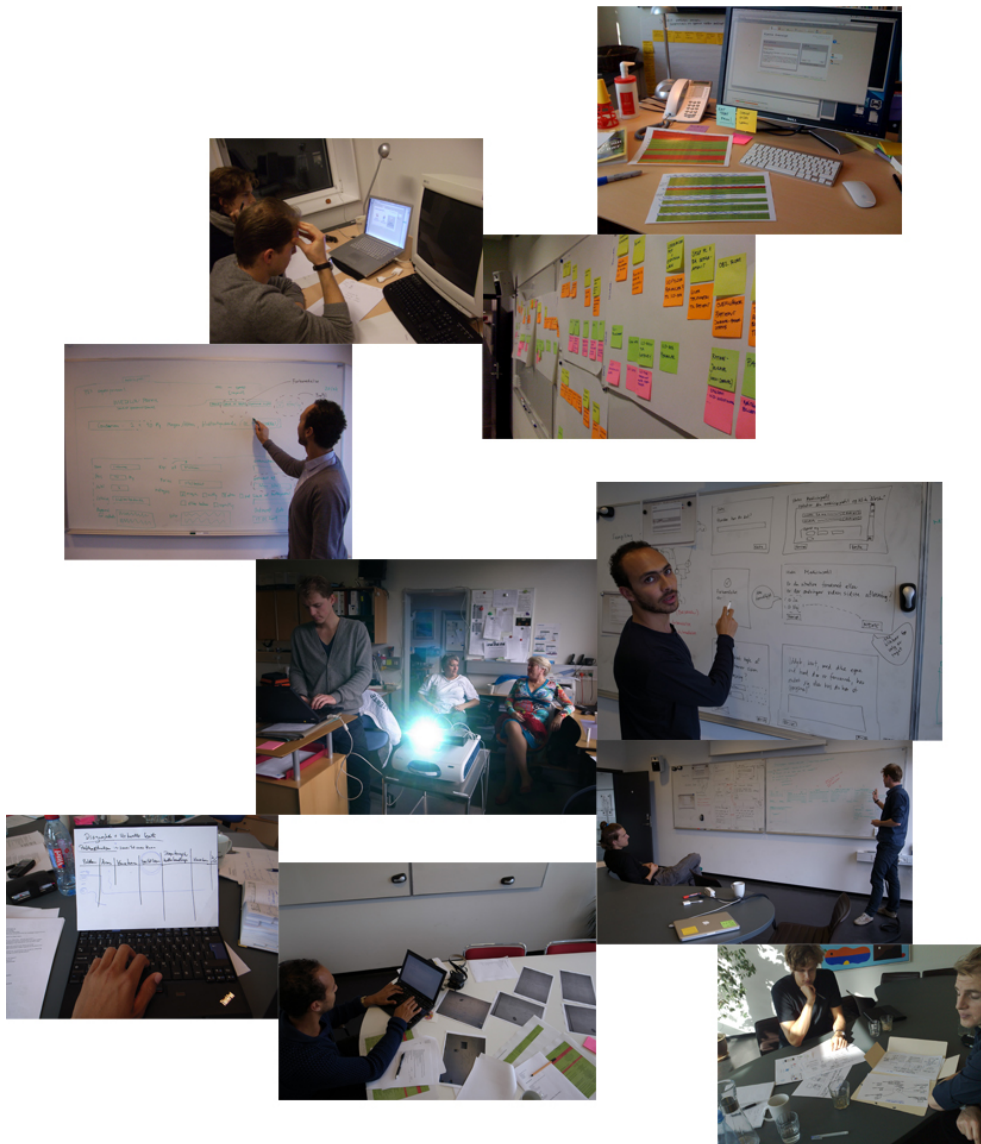
He showed us the last paper mail-reply he received from making an ICD transmission to the Heart Centre: *“it is not very informative; it only says that the system is found well-functioning. Sometimes I don’t get a reply and when I ask them why they tell me that no news is good news”*. He explained that it is not a problem now as he is feeling physically well but there have been times where he wished for more informative feedback. With these reflections, he succeeded to make clear, something that resonated in other co-design activities; that reads what patients write; what kind of reply can be expected and is it related to any action.

Internal design research sessions

Soon after, we held internal design research sessions and project management meetings (Jonas Moll, Finn Kensing, Mie Larsen and Pernille Bjørn). They were the type of design research activity that provided a space for not only continuous ad hoc project management and organisation but also a space where design, analysis, and a range of heterogeneous ideas and discussions could thrive and be debated. In one of the early meetings we all shared notes and main insights from co-design sessions, patient home visits, clinical work, and early analysis of what patients had written in Diary. We used these insights together with printouts from the prototype and the latest version of the collaborative document, ‘design concepts’ to narrow down and prioritise which features to sketch for development in the following, second, version of the prototype. One meeting that proved to be particularly relevant was a meeting with Pernille Bjørn at the IT University in Copenhagen in late January 2010. Pernille had spent time at the Heart Centre studying the differences between in-clinic device follow-ups and follow-ups that were carried remotely i.e. the new telemonitoring setup where ICD patients are monitored from a distance. We met to align our design research questions and to discuss which features could support our inquiry process as well as the patients’ and health professionals’ practices¹⁸.

I will return to this meeting and what followed in more detail below, but it is relevant to note that we left the meeting agreeing to challenge the new telemonitoring setup by integrating what we had learned from her workplace study from the participatory design activities. In general terms, we discussed whether we could bring back the patient in the process of interpreting data by letting patients and clinicians participate actively from a distance by using the prototype. We were interested in exploring what patient-generated contextual information could do for the work of data interpretation carried out by the bioanalysts at the Heart Centre and whether this collaboration could qualify the treatment and the individual responses to the patients.

¹⁸ Another reason for meeting was that we knew from earlier meetings that we shared interests in doing action research (an approach where research is brought to impact on participants’ practices and design work is introduced as part of research by employment of interventions).



Collage of pictures from design research sessions

A few days later Finn, Jonas and I met to revise the various collaborative design research documents and make a prioritised list of features to sketch/re-sketch and implement in the second cycle. The list of concepts to further co-design and develop came to be as follow: (1) Individualised Follow-ups, (2) Preparation to medical consultation [re-make of 'Summary' in v. 1.0], (3) Diary [re-make of 'Dialogue' and 'Experience' in v. 1.0], (4) Medication Profile, (5) Events and (6) Personal data. The following two months we worked hard to involve patients and their relatives as well as healthcare professionals in workshops, co-design sessions and sometimes telephone calls. We continued refining the various documents, identify, contact, and enrol patients (extended

in paper 4) and sketch and make handovers to Anselm, the prototype developer. Since these somehow secondary activities turned out to be conditioning to the unfolding of the project, the design and research, I will return to them in greater detail in below.

Co-design workshops with health professionals and patients

To present how we engaged co-design workshops as a practical way of designing on the project I will present the main insight from three early workshops. Again, co-design workshops are key activities that have been applied throughout the project and have been actively shaping the design and research of the prototypes. Apart from the co-design sessions in patients' homes, we had begun arranging a co-design workshop with patients at the university and two co-design workshops at the Heart Centre; one with cardiologists and another with bioanalysts. We developed the workshops to mobilise experiences with current use and activities of collaborative re-designing current features (e.g. Diary and Summary in v. 1.0) but also to qualify the new features of v. 2.0. The workshops worked well as venues for negotiation of expectations around certain features. They helped to identify new work practices that potentially would (or should) emerge when launching the prototype as a collaborative tool for patients and health professionals.

The co-design workshop with six participating patients was structured in two parts. In the first part we discussed their experiences of using v. 1.0 by collaboratively mapping situations where the feature was/could be necessary, what data is/could be involved, what features the patients would like and using what media (numbers, text, sound, video). One patient (woman, age 54) said in the roundtable introduction: *"I haven't really had a use for it because I feel well and don't experience symptoms – but then when I started to feel symptoms I started to write it down, which was helpful, especially because it helps you remember"* (Transcription of workshop video recording, February 2010).

Another patient (woman, age 54) said she found it difficult to make use of what she had written when she was preparing for going to a heart scan: *"It becomes a terrible mess. I would like to be able to search for where I have written 'heartbeat' and then copy it over and relate it to the heart scan. I had to bring a piece of paper with the questions anyway, the system does not support sharing them"*. A patient (man, age 61) agreed with the other participants and said he had bad conscience not having used to prototype that much and added: *"why am I on Facebook everyday but not on this system?"* It was added that the interest of being able to socialise using the prototype could be valuable (man, age 55): *"Since you no longer go to the Heart Centre for follow-ups [it is now telemonitoring] you no longer meet others who are in the same situation. Just because you get a machine, you don't become a machine. I feel isolated because the only relations to other ICD patients are through Rytmeboksen and Hjertenyt [member magazines]".* Somehow similar to the other participants he said that his use of the prototype has been limited because he had struggled with other diseases. In

this workshop, it was aired in roundtable discussions, that non-use is a design seed. There are situations where you don't want to use it often in relation to when you feel well or are too ill to use it.

When we started to map experiences using post-its and A3 posters on the wall, several patients agreed that it is useful to write down questions *"because if you don't do it, they are lost"*. We discussed the relevancy of being able to send the questions before an in-clinic meeting and one of the patients said: *"Yes, it would be easier if you can send before the meeting, because in my most recent consultation the doctor was totally unprepared and used a lot of time on flicking through my record"*. Another patient (man, 62) said; *"what we write is what the doctors are interested in"*. Finn, from our team, responded that the clinicians are not ready to read long pieces of patient-generated text and added: *"We must find a form making it a tool for you, and making parts of what you write becomes a tool for doctors"*. One patient (woman, 56) replied that it goes both ways: *"we also need to receive replies from clinicians in a form that we can use – such as seeing changes historically"*. We discussed how diary text (such as symptom experiences or worrying) could have multiple recipients; *whom am I writing for?* But also how the same piece of diary text can be useful in different ways in different situations. This was further explored in workshops with clinicians, as I will present below.

In the second part of the workshop we separated activities into three groups where we co-designed three new features: (1) Individualised ICD transmission replies, (2) Medication Profile and (3) Personal Data. As a way to prompt discussion we brought large A3 collages and screenshots of v. 2.0, empty of content and functionality. We were interested, similar to the patients in the co-design sessions, in identifying situations to where a list of medicine could be relevant, what functions were needed (i.e. buttons, links and menus) and what content should be available or possible to generate. Among other things we learned that a self-generated list of medicine should be sharable with clinicians i.e. send before a meeting or print and bring along and that a list is useful when taking medication (i.e. history of medicine list, an alarm reminding you to take medicine, indication of which drugs are eligible for refund, the primary effect of the drug etc.).

When working on re-designing replies from remote ICD follow-ups (telemonitoring) we used A3 printouts of a patient's reply to discuss current problems, situations and desired content of a reply if it was part of the prototype. Several patients wanted to know the background for why many of the replies only informed; *"the system is found well-functioning"*. They also asked for a more detailed description on the current status with a more human-centred focus in contrast to the current technical focus (i.e. not only providing information on *"the system"*). The majority wanted information on battery time left: *"How much battery is left in months?"* and *"when is there a need to take action"*. Some patients also expressed concern for knowing too much and

suggested to keep details hidden but accessible: *‘It’s an individual balance how many details you want’* and *‘I don’t want to know too much, it just needs to work and if it’s important they should call me’*. Some also wanted to know about the status of the electrodes and how active the ICD has been (i.e. has there been events).

When we suggested the personal profile to include a picture, name and social security no., address, relatives contact information and basic data on the ICD device (type, brand, implant date, changed date, etc.) it was well received but when discussing patient-generated data one patient commented: *“the question is whether health professionals will use the information I enter? Is this a record no. 2? And who should be made accountable for updating the information?”* He suggested being alert on redundant registration of data. We also presented the idea of having an address book of clinicians currently involved in one’s care and one patient responded: *“It changes all the time who I see – for example now I’m on my 5th doctor”*.

From this workshop we had created concrete material that worked productive for giving shape to the prototype v. 2.0. The annotations on the A3 printouts supported the work of sketching website architecture and prioritising the layout of features. As a way to link development (web-programming) of the prototype, we invited Anselm, the developer, to most of the co-design workshops at university, as a way to give him a good impression of where the design-features arrive. As a continuation of the participatory design of the prototype v. 2.0, Finn, Jonas and I held a workshop together with a cardiologist from the Heart Centre and a cardiologist from Bispebjerg Hospital, where some of the ICD patients receive medical consultations. The aim of the workshop was to qualify the idea of patients preparing for consultations and remote ICD transmission follow-ups by using the prototype. We knew that introducing long text passages written by patients is not doable simply because clinicians do not have time to read it. We therefore headed the workshop with “focus on questionnaires” to indicate the ambition of supporting patient-clinician communication (which was the theme of design research experimenting in v. 2.0).

Just after Finn had introduced the workshop one cardiologist emphasised what we had already discussed with the patients: *“we need to be sure that it’s clear to the patients that if they write novels, we don’t read it. The patients’ expectations have to be very clear: they can only expect we know what they provide in questionnaires and not their personal or shared diary in the prototype [indicating that patients could possibly share their diary with other patients]”* (Transcription of video, February 2010)

When we presented examples of what patients write in the prototype one cardiologist reacted on an example of a patient-generated medication list: *“It is*

extremely important that we [clinicians] can be certain about what medicine the patient actually takes – whether it is written by the patient herself, a GP or a local hospital, just make us having to check more lists. I think my message is, that the information coming from patients need to be something we can trust. Of course the patient himself knows best what he takes and therefore it would be very important if patients ‘check’ or ‘approve’ their version of a medicine list. They should also be able to comment and add deviations such as ‘I have stopped taking this drug because I get stomachache’. The cardiologists agreed that the most important information to communicate is the relation between prescribed medicine and what the patient actually takes. This point was also made in the co-design workshop with bioanalysts, which I will present below. Moreover, as described in paper 1, it developed into an “approve-button” enabling patients to signal that “this is the list of medication I currently take – and these are the possible side effects and symptoms experienced”.

One of the cardiologists explained that they have a project where they study Quality of Life in relation to remote monitoring. We suggested that the prototype eventually could become a platform to support research projects by enabling easy ways of collecting data from patients. They agreed that it would be useful, but that the population using the patient platform might not correspond to population needed for a study. One cardiologist said that he was currently running a research study with multiple questionnaires, which “*we mail out 14 days before and ask them to fill out*”. It is part of their normal consultations but “*of course I flick through them to see whether the crosses are to the left or to the right – it actually becomes a supplement to what I need to talk to them about. It is reaffirming if the crosses are to the left, because then there are no problems and you don’t need to spend that much time on it.*” It was suggested to make a score such as the Kansas City Cardiomyopathy Questionnaire that could support medical consultations: “*We don’t use it [questionnaires] regularly and that’s not because it’s not useful but because we don’t have any tools or tradition of doing it*”. Interestingly, one cardiologist envisioned patient-generated information as a source similar to lab results and the medical record. This underscores the interest in patient-generated data and the importance for clinical work, that it is translated in to a form that is actionable.

The cardiologists agreed that it is an ethical challenge to manage patient-generated information because if patients write something in the system that is important but not received or read by clinicians it is troublesome. As a solution to this the cardiologist emphasised the need for separating what is read from what is not read by clinicians. In relation to medical consultations it was suggested to introduce the question: “*what is the most important we should to talk about today?*” and then have only 5 input fields to fill in. In addition to patients agenda it was added that cardiologists also have an agenda: “*we also have an aim with the consultation*”.

We continued to present other patient-generated quotes and discussed the need for patients to be able to categorise, with their own categories (such as chest paper, abnormal heartbeats) and that it is particularly useful for clinicians if they have a history of categorised text as opposed to free-text. One of the cardiologist added: “I also think it’s important for patients to have a ‘no discomfort, I feel well’-category. It doesn’t work if is by not writing that they signal they are well. I need to be reassured about their health status also if it means that they have to log on and select it”. The cardiologist suggested that one way of implementing ‘patient preparations’ would be by asking them ‘has your situation worsened?’ and if they select yes they are presented with a list of symptoms to select. This would work as selection support for e.g. bioanalysts doing remote follow-ups and in general: “we don’t want know ‘yes’ if there is nothing to note and we don’t want to overlook that a patient actually have written something important”. These ideas were all mobilised and became part of the second version (see paper 1). That is, the wishful, yet critical, thinking was materialised in v. 2.0 to see how it would perform when installed as part of the medical practice. But for now, in the workshop, it was merely representations or envisionments of ‘what if’.

Since we were working on making the prototype a collaborative tool between patients and clinicians we still needed to qualify the concepts that involved remote follow-ups of ICD transmissions. The co-design workshop with bioanalysts, who do the daily monitoring at the Heart Centre, was therefore a way to present and discuss possibilities for making individualised replies to ICD transmissions but also a way to involve bioanalysts and their suggestions as of how to make use of patient-generated data in relation to situations where they review device data. In this workshop, which I present here, four bioanalysts participated and it was set up in their office at the Heart Centre. Similar to the workshops with cardiologists, we brought snippets from patients’ writings and presented the first version of the prototype. However, this time we were able to show them early sketches of webpages of v. 2.0. We introduced the workshop by explaining that we were focusing on two things: what information the bioanalysts need from patients when reviewing device data from remote follow-ups and how it could be possible to make individualised replies and give patients more details (this was what patients signified as valuable to them).

One bioanalyst explains that patients often arrive with a note saying; *“those days I did not feel well, is it possible to see anything [in the device data?] - this would be helpful to know for us”*. Another bioanalyst adds; *“since it’s no longer possible to look the patients in the eyes, the patients who are telemonitored, it would be nice to get some information from them to support whether or not to take action. There has to be a comment if the patient has experienced problems.”* The bioanalysts agreed and said that it is useful also to know *“why are you making a transmission [if unscheduled]”*. One bioanalyst give the example that a patient had sent an email in relation to symptom experiences

and that it was helpful when reviewing the device data: *“for example if a patient says he gets sweaty when he rises from sitting down, it might be atrial fibrillation”*. The bioanalyst reaffirmed that potential for a remote collaboration between patients and bioanalysts was potentially valuable to the bioanalysts. In this way they could provide the service and care, which they were used to giving when patients came physically to the clinic.

Then we presented screenshots of early mock-ups of v. 2.0 and asked the bioanalysts what questions they would like to ask the patients. They said: *“it is important to know if patients have changed the medicine they are supposed to take”*. They started to talk about *“what is it we actually ask patients about when we call them?”* and the others replied: *“How have you been? What medicine do you take? Have you put on weight? Do you experience shortness of breath? Changes in these things – it is the same five problems we call about every time”*. They said that it is nice to know if patients experience nausea because it can prevent them from taking medicine, which in turn can lead to more events [ICD device treatments]. Turning to patients’ wishes of receiving more detailed replies the general answer among the bioanalysts was that they could provide all the data. But then they started talking about how much writing this would generate and that it would need to be automatically transferred into the replies [i.e. technical integration]. They all agreed that the information we were asking to give to the patients were not new to them: *“These are the questions the patients ask us about – there’s nothing new in that”*.

At last we suggested our idea about recording individual audio messages to patients where action is needed. One of the bioanalysts says: *“If it can prevent me from having to write, It’s OK”* and another says *“In a test period it would be worth trialling – both for us and the patients”*. However, they added that the problem of making it available in text/audio would potentially mean more work because *“then we need to go back – what did we tell him last time?”* Similar worrying was present when we asked to provide battery status to the patients: *“It has to say that ‘we expect’ the battery level to this and that, because it varies a lot and the patients remember this. Battery status is a difficult one”*. We ended on making three categories that they could agree upon: *“more than 5 years, more than 2 years, and less than 3 months”*. Similar to the workshop with the cardiologists, the bioanalysts were willing to experiment but at the same time they were very much worried, that having to make individual replies could potentially become overhead work. The introduction of telemonitoring had made this service or care difficult to undertake and the time to do it has almost already been deleted. In this discussion, the bioanalysts made clear, that for patient-generated information to ‘work’ it had to be in a form that is readily actionable using the prototype.

We iterated on the overall concept of building a collaborative tool to support communication between patients and, in this case, bioanalysts making remote follow-ups. One bioanalyst responded: *“It the system can help us not needing*

to call patients to get the latest details, or the patient has to call in just to say ‘now I’m making a transmissions for this and that reason’ – if they know this is the way we do it [using the prototype] then it will make it a lot easier. Because they are also frustrated not being able to get through [the telephone] and we run around, busy answering the phone”. This snippet indicates the affordances, which the bioanalysts imagined a patient platform could provide. Again, this adds to how they experienced the prototype as a mix of potentials bringing good and worse things along. This latter snippet and the work related to new categories of work introduced by telemonitoring practices, are discussed in terms of Oudshoorn’s (2008) *inclusion work* in paper 1.

Launch workshops

A range of in-between design research sessions at university followed these workshops. Here, we engaged re-design of v. 2.0 by sketching and finalising screen mock-ups to hand over to the prototype developer. In the time between the co-design workshops we watched selected parts of videos and listened to audio recordings, which were many times (partly) transcribed. We used our notes and the artefacts created in the workshops to re-sketch v. 2.0 features and related work activities. We sketched on the whiteboard and made mock-ups and wireframes using our laptops, sometimes in collaboration with the prototype developer. The developer reported continually on progress and we held several weekly ad-hoc meetings to discuss technical possibilities in relation to the mock-ups and the timing of the planned launch. In this way, technical constraints as a combination of the developers experience and the available open source components, inscribed the paradigm of possibilities for doing this kind of design research.

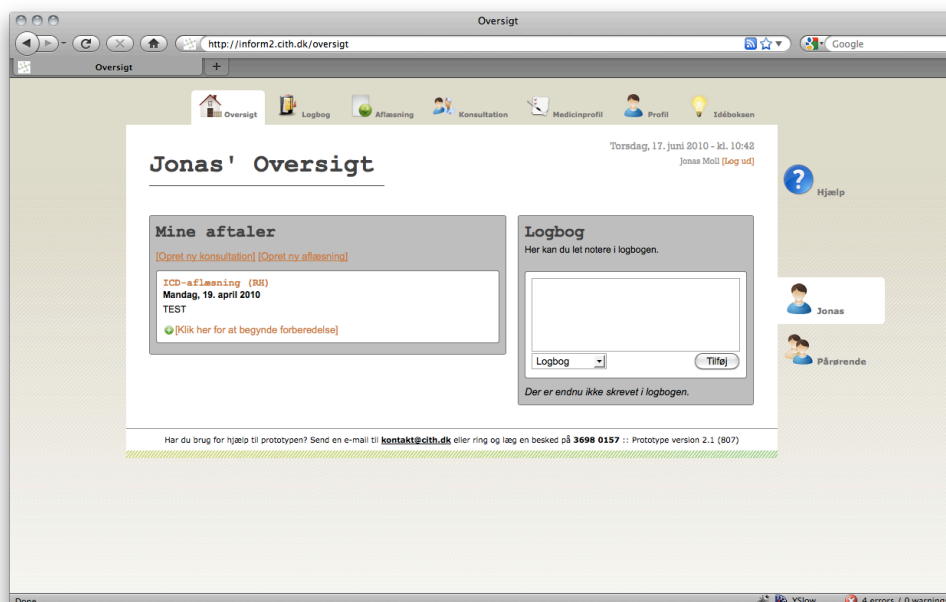
In late March the v. 2.0 was stable and ready to replace v. 1.0 (and v. 1.1) of the prototype. As a way to insinuate a deliberate move from making a platform to support patients (Diary) towards a platform to support the *collaboration* between patients and clinicians, we called the second version of the prototype *Inform*. It was accessible online, similar to v. 1.0 and v. 1.1, but this time from the URL www.inform.cith.dk. In terms of features, mainly designed to support collaboration and many different interests, the second version of the prototype was similarly radically restructured in terms of the interface and the underlying data model. The front-page describes this very well. Instead of having the Logbook feature prescribe the information architectural model, we made “events” or a calendar become the underlying information model of the prototype. This shift towards a temporal and spatial ordering of features provided a means to organise patients’ and healthcare professionals’ actions and use of the prototype. For example, it was now possible to connect patients’ generating a medication profile and writing about symptom experiences to an actual event such as a remote follow-up of the ICD device or for an upcoming medical consultation. V. 2.0 had materialised many of the interests of both patients and health professionals. The features included in the

second version include: Overview [my appointments/events], Logbook, ICD Transmissions, Medical Consultations, Medication Profile, Personal Profile and the Idea box [where patients could write if they had suggestions]. We also included a tab called “Relatives” to signal that we were working on ways to include family members in the platform and provide them with features that could support their interests. We, as well as the patients, recognised the importance of designing, not only for patients as individuals, but for patients who have relatives that in some cases, are more knowledgeable, reflect more and take more action than the patient herself. Relatives were therefore always invited to workshops and were asked to take part in co-design sessions.

These features in v. 2.0 were to a large extent materialisations of patients’ and health professionals’ interests and their ideas for design solutions. It includes; sharing patient-generated information in short and actionable forms, storing basic person-data, letting patients generate their own version of their medication profile and approve it, and so on. The different features (web pages) of the prototype and the layout and the actionable buttons and dropdown menus contain themselves many stories and links to the involved participants on the project. Those features we did not have the time to implement or were uncertain about, we included as “dummy features”. Instead of implementing functionality of for example Network; being able to communicate with other ICD patients, we included an image as if the feature was implemented and to simulate ‘what if this was possible’. In this way, we could prompt discussion and conceptual refinement when carrying out design interventions (as will elaborate further below). We expected, that it might also work to signal that we actually take serious and do what we can to implement the participants’ desired features. It could additionally serve to motivate and *interest* patients and healthcare professionals – an art that is fundamental to doing participatory design, or innovation as such, and which deserves much more attention on projects like ours (see Akrich et al., 2002; Callon, 2005; Pedersen, 2007). We also discussed another way of making *interesement* and visualising the inclusion of the participants and acknowledging their collaborative contribution; scripting a mouse-over event that, when you move the mouse cursor over a feature on the webpage, presents the first name of the person who originally suggested the idea. Another way of including participants was to communicate features using help videos. We did not have this ready in v. 2.0 but succeeded to produce such videos and install them in v. 3.0, letting patients watch from home, what they could do and how to use the patient-centred web application.

But again, what the prototype also afforded was a means for us as design researchers to carry out methodological experimentation. As design research hardware, the prototype supported our interest of making experiments with integrating ethnographic inquiry and cooperative design. And, for the reasons of the argument put forth in this thesis, describing the features of the

prototype is not of primary focus, but that is the methodological experimentation we engaged in. Therefore, I will present the papers and the related methodological discussions below in the main body of the thesis.



Screenshot of v. 2.1 of the prototype, *Inform*

Nonetheless, as with the first version of the prototype, we planned to launch a refined version (v. 2.1) of v. 2.0 a month later with another group of patients. In this way we could catch errors and the learning from the first launch workshop and make minor adjustments for a 2.1 version. These launch workshops worked well to get early feedback on immediate experiences and helped us to better introduce and explain about the features of the prototype. However, as with any other workshop, co-design session or design intervention, it demanded a tremendous effort of planning, shopping, updating collaborative documents, calling and emailing and thus enrolling participants, and technically making use of the prototypes a reality. This is discussed more below and expanded in paper 4. The features that came to be part of v. 2.0 and 2.1 and accessible on www.inform.cith.dk were: Overview (appointments), Personal profile, Logbook, Medication profile, Guidance and Ideabox.

Design interventions in patient homes and hospitals

As the second version of the prototype, *Inform*, proved to become a platform for patients and health professionals to communicate and ‘inform’ each other from distance, the first steps were also taken towards *actualising* the prototype *in use*, as opposed to the more traditional mode of doing participatory design i.e. by envisioning or simulating use. This potential led to the development of a new type of design research activity: *Design Interventions*, which are central to the contribution of this paper.



Collage of pictures from design interventions in patients' homes, the Heart Centre at Copenhagen University Hospital and local hospitals.

Design interventions came to be situations in patient homes or at hospitals where participants not only co-designed, envisioned or simulated use of the prototype (as in the classic understanding of cooperative prototyping) or where we as design researchers could observe potential new activities, critically question situations of use or suggest re-designing the solutions. Design interventions became situations where multiple practices – traditional and transcended, came to co-exist, and where we, initially, faced the challenges of managing interdisciplinarity. This, I will return to below.

The ambition of making methodological experiments and performing a mix of ethnographic practice and participatory design practice created a host of philosophical and practical tensions. The tensions coming out of this ‘disciplinary clash’ felt, at the time, rather *unproductive* for our process or as obstacles for keeping momentum on the project. But, these ‘tensions’ provided material for philosophical discussions and were in this regard, also rather *productive*. Therefore, as I will present below, these tensions came to be constructive vehicles for making practical and empirical insights and developing answers and suggestions to how ethnographic work and design work can be fruitfully assembled. In the following, I will use the thesis’ papers to bring forward the (un)productive tensions we experienced and prepare for the thesis main argument in Part 3.0. As for now, I leave descriptions of participatory design methods, tools and techniques to instead foreground the methodological or philosophical discussions that have permeated all aspects of our work.

(Un)Productive tensions A

Now, in April 2010, where v. 2.0 and 2.1 of the prototype were launched, the project had gained decent momentum and we were getting closer to actually carrying out design interventions with collaborating patients and health professionals. The design intervention and the evaluation of the action research study were also about to happen. In this section I will expand and discuss paper 1 and paper 2 of the thesis. That is, not by an elaboration of the contribution of the articles, but rather by foregrounding the (un)productive tensions between design and research. I will present the main reflections that (for many reasons) are not included in the journal article and the paper but which discuss the methodological concerns we faced while doing the action research study and the early design interventions. In this way, the two papers and the work of making them, continues the master narrative of this extended synopsis – the unfolding of the project in connection to knowledge production and brings forward some important points for the methodological argument in this thesis. I refer to the first two points as: ‘Convergence of design and use’ and ‘Participatory design as ethnographic work’.

In the first section, ‘Design and use converge’, I discuss the methodological tensions we experienced while applying a combination of Information Systems’ (IS) action research and Participatory Design. I suggest, that action research (and design science) as principally practiced in IS are poor choices if the agenda is to design something that is relevant for selected users. Said in another way, Checkland and Howell’s (1998) version of action research is possibly useful to evaluate technologies that have stabilised but they do not offer constructive approaches if the aim is to explore, experiment and enact innovative solutions to current healthcare problems. The argument being made is for the fruitfulness of sidestepping a representational mode of engaging design to focus on designing as an actualised part of a use situation. This is how I define the convergence of design and use.

In the second section, ‘Participatory design as ethnographic practice’, I bring in paper 2 as a way to suggest seeing participatory design activities as (part of) ethnographic practice. That is, instead of performing participatory design and ethnographic work as separate disciplines, I propose co-design sessions and design interventions with working prototypes as valuable methods for carrying out ethnographic practice.

Realistic lines between design and ethnography [Paper 1]

Organising the first (design) intervention at the Heart Centre was not just a complex task of preparing for design. It turned out to become a huge practical, organisational and political achievement. We had to negotiate with the bioanalysts and individually communicate with 23 patients when setting up a situations of use and design of the new feature in v. 2.0; Preparing for ICD

Transmissions. With this feature, patients and clinicians at the heart centre could communicate (asynchronously and remotely) with each other. The ‘getting ready to try it out’, turned out to contain a long range of activities; everything from informing the participating patients on what they needed to do with the prototype and at what time – to thinking through how to engage the prototype at the Heart Centre and integrate it into the current way of doing remote follow-ups. Getting ready also meant calling up patients the night before to remind them to make a transmission and use the prototype. As well as it meant creating screenshots of all the patients’ writings, printing these and arranging them to be ready to present at the heart centre. All this work grew in matter and became very much centre stage for us. We were surprised at how much time we spent doing ‘everything else’ – all the work, which is seldom included in method sections of research papers in e.g. PD and CSCW.

We discussed the large amount of work involved in convincing and coordinating participants, aligning material, artefacts and setting up the prototype to run smoothly, just to be able to carry out a couple of hours of workshops or design interventions. Inspired by Jens Pedersen (2007) we found this work to be a category in itself. We agreed that in many ways it is such invisible work that conditions and eventually co-constitutes participatory design wherefore it must not be overlooked. Since we continued wondering and questioning this category of practical work, ‘practicalities’, we decided to submit and eventually facilitate a conference workshop at the Participatory Design Conference 2010 (Andersen, Moll, et al., 2010) and write a paper on the subject (paper 4). The main points derived from this work are part of the thesis argument and will be presented below.

We succeeded in getting the practicalities in place and as a consequence, the design intervention at the Heart Centre turned out well. It was successful, partly because we (patients, clinicians and design researchers) succeeded to perform remote, *collaborative* patient-clinician follow-ups with the prototype and partly because we (design researchers) could bring back empirical material that could feed into our action research study. Again (similar to making the design intervention a possibility), this seems straightforward and I could have left the methodological assumptions as described in the journal article. But looking back it was not that straight forward to translate the empirical material from the design intervention and write it up as an action research study. Of course, one of the challenges was the analytical work itself and writing up the article. This is, although, quite common to the work of making a scholarly contribution and it is not what I will bring forward here.

The first tension that that I will draw attention to relates to the main questioning of this thesis, namely; *how can research (such as an ethnographic study of patients and telemedicine) and design (such as co-designing and using a prototype) be fruitfully assembled?* As I have described above, we chose to work with a version of

action research (Checkland and Holwell, 1998), popular within IS as a way to frame and integrate fieldwork observations with a design driven intervention.

The ideal model of practicing this version of action research is *sequential* and is to some degree *systematised*. It rests on *separating* problem and solution (“diagnostics and therapeutics”) (Andersen, Bjørn, et al., 2010, p. 115), which in many situations can be fruitful such as when improving conditions for collaboration by rendering some phenomena articulate, intelligible and rhetorically convincing. It is, nonetheless, recognised that the cyclic nature of action research means that the main action cycle consists “*of a large number of small action cycles, each entering the ring of understanding, intervening, and evaluating*” and that the stages are “iterative interrelated” (ibid.).

Checkland and Holwell argue that it is not possible to match the natural sciences’ principles of validity and reliability completely¹⁹, and suggest that action research should compensate for the shortcomings of a epistemology that is declared in advance of the intervention and that it should include the criteria of “recoverability”:

“AR [action research] should be to enact a process based on a declared-in-advance methodology (encompassing a particular framework of ideas) in such a way that the process is recoverable by anyone interested in subjecting the research to critical scrutiny” (Checkland and Holwell, 1998, p. 18).

As a way to construct a well-organised ‘truth claim’ in action research, “*the epistemology (the set of ideas and the process in which they are used methodologically)*” needs to be worked out *in advance* in order to be able to say, after the intervention, what counts as acquired knowledge (Checkland and Holwell, 1998, p. 20). While this is very useful in terms of positioning the study and making it possible to communicate results, I would argue, that it does not render research, the prototype and the intervention any closer to the ‘truth’. In other words, separating what is known before from the solution created (the prototype) and the intervention of use and design itself only makes it possible to make a rhetorical argument. The power of action research lies not in working towards producing ‘valid’ or ‘recoverable’ truth claims but moreover to develop a socio-technical assemblage that has done something valuable in some practice. Aspiring to clean lines between fieldwork observations, analysis,

¹⁹Checkland and Holwell (1998) argue that carrying out change oriented research involves accepting that “social reality” is not a given and that the researcher is immersed in what is under study. For these reasons, it is not possible to achieve validity as in natural scientific experiments and they suggest a workaround by posing the question: “*Can the method of science be applied to material which is not homogeneous through time, making complete replicability impossible? If not, what else can be done?*”.

and participatory design evokes a realist account but certainly not a realistic one²⁰.

Now, writing up the study and following the framing of action research, it became clear that we had only followed the protocol to some extent. Before intervening with the prototype we had agreed on what it is we wanted to try out – in the article this is described by our joint research questions: *“Why do clinicians experience problems interpreting ICD data when the patient is absent, and how can patients be re-introduced into the socio-technical setup of telemonitored interpretation practices?”* (ibid.)

And after that meeting (before we had a working prototype), we continued the participatory design process. As I have described in much detail, working sequentially was not the actual case when developing v. 2.0 of the prototype (i.e. what do we know now and what methodological procedures will we apply). Developing a coherent understanding of the current problems was, in realistic terms, inseparable from the design activities, the prototype and the intervention. The design of the prototype was not an off-the-shelf technology that we installed to evaluate the outcome. It was designed, partly by us being informed of Pernille’s fieldwork observations, and partly by implementing the participating patients’ suggestions. But moreover, during the intervention where we had installed the prototype in use, we did not come as evaluation experts. We came along, also to let the bioanalyst help formulate how remote follow-ups could be otherwise – i.e. designing in use, not just evaluating through use. As it happened, the solution and the problem of patients being absent were in our participatory design activities, such as the intervention, interwoven and not separated as action research prescribes.

Aspiring to clean lines between ethnography and design is not what we want to enact because first of all we found it unproductive in the case of the referral, and secondly, because we were pushing for a process of integrating them. Keeping action and intervention separate re-installs the classic rational and realist connection that we found unfruitful when studying and designing for the referral (part 1.0). It is similar to the idea of workplace studies *informing* design by articulating implications for design – design and research are described as being a ‘one-way street’. Methodologically and epistemologically such framing aspires to the power of the natural science method of knowledge production, which is fruitful and very powerful for other purposes than designing a useful tool and researching it ethnographically.

So why formulate the study in general terms that evoke a rationalist and realist sequence of activities as suggested by Checkland and Holwell instead of aspiring to a *realistic* account of how the activities of ethnography and design

²⁰ The tension presented in this section is very much inspired by science studies ‘unpacking’ of what scientists do and the thinking of what Latour calls realistic realism (Latour, 1999; Latour and Woolgar, 1986). I will introduce this line of thinking in more detail in part 3.0.

were (and importantly, conventionally, *are*) not sequential and separate in nature? The main reason is that we were undergoing a transformation in terms of methodological application. In fact, we were experimenting with how design and ethnography could be fruitfully combined. Moreover, framing the study as action research is a more conventional method when making a contribution to the research field of medical informatics. Open-ended and design oriented methods that integrate ethnography and design, such as *research-through-design* (which I shall introduce below), are still somewhat immature and have not travelled far enough to engage audiences in CSCW and medical informatics. They have not been established as legitimate research approaches. We believed the situation to be somewhat similar in regards to participatory design methods. Writing the article in a research-through-design or a participatory design framing was therefore not a workable option. It would challenge the review process and make acceptance more uncertain.

The productive element of this tension is that I can suggest only using Checkland and Holwell's model of action research, if one has the ambition of keeping clear lines between 'research' and 'design'. Said otherwise, and as formulating the first proposition:

Proposition 1: Realistic lines between design and ethnography

*I propose to aspire to *realistic* lines between ethnography and design and to be pragmatic and sensible to what works in practice (.. and to be realistic about that when writing it up)*

Convergence of design and use [Paper 1]

Another tension, which emerged as part of writing up the action research study, is rooted in the same methodological frictions between Checkland and Holwell's (1998) version of action research and how design and fieldwork observations realistically unfolds. The challenge was to, in writing, conceptually separate the features of the prototype from the intervention and the participatory design process where patients had been using the prototype already. In other words, following the protocol of action research we needed to describe the features of the prototype in terms of 'form' and 'function' so that we could rationally evaluate the consequences of its introduction in to use as part of a design intervention. But what had happened was that describing the prototype in generic terms had become strange to us. It was uneasy to describe the features as 'standalone' and away from use. This was the opposite situation when we launched the v. 1.0 and where the prototype only existed as being away from use. In the time of launching the first prototype it was designed to be more open-ended and to encourage appropriation and configurability through patients' use. We were very curious about what the prototype would be like when *in use* because this has not yet happened and 'use' had only been something we envisioned.

Before the participants began logging in from home and began to write down their health care experiences, the prototype only existed as sketches, concept descriptions, and code running in our environments. At that time, only representations of the prototype web-application as standalone, could be found. No patient had used it yet and it was not part of any practices outside co-design workshops. So, at that time, it was difficult the other way around. At that time, we had to construct *visions* of use because no patient or clinician had used it. Now, in writing up the action research study for the IJMI special issue, it had become difficult to unravel the many experiences from co-design session and design interventions where patients and clinicians actually used it. After the prototype had been ‘out-there’ for a while the different features of the prototype began to exist mostly as in relation to situations of design and use (such as in design interventions). Describing the features of the prototype in general terms was again being unrealistic but also somehow strange, because for us, the features had not conceptually stabilised – they were all the time contested making it most meaningful, at that time, to describe the features by examples of use.

The tension created from separating the prototype features from situations of use, made clear that we, together with patients and clinicians had performed a convergence of design and use. The exercise of conceptually separating features from use revealed that the prototype had eventually become (more or less) embedded in different practices – at least in the time of the design intervention. Writing up the features as something that is apart from use made it even more present – all the work that had gone into connecting the prototype to contexts in a meaningful way, now had to be omitted to enact a sequential and evaluative approach to design research (i.e. action research or design science²¹). Describing the prototype by its “affordances” and in ways that present it in terms such as how use is “envisioned” or “anticipated”, create a shift in attention.

Focus is moved from working on *designing* the prototype towards *evaluating* the prototype as a finished and stable design. This focus is reasonable in many cases, also in our case of conducting an action research study. However, describing the features in functionalistic terms erases all the design work that the participants and we had worked so hard to create – and still were doing. It induces an approach where evaluation of a design is the main concern and where the ambition to understand more about something is determined and defined beforehand. This could be *how easy is it to use it?*, *how fast can the user accomplish some task?*, or as in our case; *what are the consequences of re-introducing patients in remote telemonitoring practices through a collaborative web-application?* Again,

²¹ Design science as developed in Information Systems inherits the underlying ‘truth’ logic from some versions of action research, making the objective of “design” evaluative as opposed to the objective of designing something that eventually can be evaluated (see e.g. Baskerville and Wood-Harper, 1996; Hevner, A. et al., 2004).

this is useful when the objective is to evaluate something that has already gone through a design research process and when problems (and solutions) are considered as stabilised and made more or less definite – as we eventually had to do in our case of the action research study. Shifting from doing participatory design to include ‘scientific’ evaluation makes the design-in-use process fade into the background of the action research study and focus is again shifted towards aspiring to scientific rationality.

This tension of separating the prototype from use made clear, that aiming to produce results that are “recoverable” involves a mode of design research where use is defined through design as opposed to a design process where use is defined through use. In other words, the idea about what design is, is reduced to a material object, out there, made without any particular practical effort. Design as an activity that works by connecting future possibilities with the current situation is out of focus. What matters is the evaluation of it, not so much how and in what ways good design is actually produced.

Now, acknowledging that we were very much engaged in design and not evaluating-without-designing I would like to introduce the idea of design-in-use. For this reason, I turn to design theory. Redström (2008) calls it “acts of defining use” drawing attention to the different ways in which design processes perform or rehearse the relationship between design and use. He starts with the idea that design is about “thing-design” and “use-design” and exemplifies it by the design of a chair:

*“[W]e design the chair as a physical thing [thing-design] but, in doing so, we also design a particular act of ‘sitting’ [use-design] [...] ‘Defining use through design’ is, for instance, what one does when expressing a specific notion of what it is to sit through how a chair is designed. Defining ‘use through use’ is what one does when using the chair to sit – i.e., when someone defines what a given thing *is* by using it in a certain way” (Redström, 2008, pp. 412-413).*

In Redström’s theory, the tension appeared because we were undertaking a design process where use-design as well as thing-design happened in use. Instead of approaching the design-use relation by applying participatory design methods and techniques to *bridge* design and use we were increasingly involving participants to opening up for “use as design” or “design at use time”.

Ehn (2008) brings this line of thinking to Participatory Design and borrows from Redström to call it “*meta-design (designing for design after design)*” and contrasts it with traditional participatory design (designing for use before use). Traditionally, PD is employed to overcome the “*design challenge of fully anticipating, or envisioning, use before actual use*” (Ehn, Pelle, 2008, p. 92) and the

benefits of working with representations and envisionment has been a cornerstone of the Participatory Design discourse. Kyng argues:

“The main quality of representations of the system being designed is that they allow the end users to carry out work, to simulate working in the future with the new system [...] In fact, most representational artifacts work so well not because they mirror that which is represented, but because they do not, that is, the representation captures a few intentionally selected qualities of that which is represented and nothing more” (Kyng, 1995, pp. 46, 48).

Certainly, we have been designing in a ‘representational-mode’ (on co-design workshops and by co-sketching features of the prototype) but with the design intervention at the Heart Centre and the writing up of the action research study, we realised that we had moved into doing “design in use”. Dittrich et al. (2002, p. 125) explains this as a way “to capture practices of interpretation, appropriation, assembly, tailoring and further development of computer support in what is normally regarded as deployment or use” (For strategies that place design at use time see also e.g. Hartswood et al., 2008; Karasti, 2001; Suchman, L. et al., 2002).

We realised that we had succeeded embodying the design exploration of possible use into situations of actual use and thus provided for a different way of designing and researching. In Redström’s (2008, p. 421) words we had moved from more classical user-centred design of testing and trying out ‘use’ during the design process and in advance of actual use (‘use’ before use) towards an approach that attempts to create a different space of possibilities for acts of defining use through use (‘design’ after design). With the design intervention, we had opened up for a strategy that disregards the use-design relation as a problem and instead considers the relation as mutually constitutive; use is design and design is use.

Proposition 2: Convergence of design and use

I suggest disregarding the use-design relation, typically appointed as something to be bridged, and instead work towards dissolving the boundaries by employing design interventions with working prototypes.

Participatory design as ethnographic practice [Paper 2]

As a way to conceptually explore the relationship between designing before use and designing in use, I developed the figure of the ‘participatory patient’ (Andersen, 2010). This is elaborated in paper 2 of the thesis. The paper draws on Redström’s (2008) idea of defining use through design or defining use through use. The case presents Mr Norman, one of the patient participants in the project. By empirical snippets, the paper exemplifies how Mr. Norman actively participates in design and envisionment, but also how he later uses the designed features to prepare for consultations and remote monitoring

procedures. The paper exploits the implications of the duality of participation on a participatory design project in healthcare; namely that the logic of active participants in participatory design aligns very well with the patient empowerment paradigm but that it is also paradoxical in nature. Paradoxical, because by active participation in both design and use of the prototype Mr. Norman successfully inscribes and enacts an active patient – because to actively participate on the project, patients necessarily need *not* to be ill, weak or in bed. To be a patient who participates actively s/he has to be out of bed and capable of coming to the university for design workshops and using the prototype at home. In other terms, non-work, which I conclude, is an important category of patient work in relation to healthcare technology design. However, it does not surface when only actively participating patients are involved. Patients who engage in technology design necessarily have to be involved in exploring *non-participation* despite the contradictory logic.

Nonetheless, what the paper hints at, but does not discuss, is the methodological combination of ethnographic concepts and design theory to frame the connection between design and use. The paper's analytical framing is a bringing together of Redström's design theory (acts of defining use) and concepts from ethnographic studies of patient work (acts of defining "diagnostic agent" and "homework"). What drives the paper's argument is Redström's distinction between design activities that define use before use (i.e. prescribing and envisioning use) and activities that define use in use (i.e. use of the prototype to prepare for a medical consultation). But for analytical purposes in the paper, Redström's idea of "acts of defining use" is extended to be "acts of conceptualising patient work". Instead of keeping to Redström's design theory, ethnographic concepts are mobilised to frame the relation between design and use. In this way, Mr Norman does not only participate in designing new features of the prototype and in Redström's words; define use through design but Mr Norman also inscribes the ethnographic concepts of "homework" and "diagnostic agent" in the prototype. Mr Norman's use of the prototype to prepare for a medical consultation and telemonitoring procedure becomes not just what Redström calls "defining use through use" but moreover empirical enactments of ethnographic concepts on patient work. So, treating the co-design situation as sites for ethnographic fieldwork renders what Mr Norman does, analytically intelligible by ethnographic concepts.

At first, this might seem as making the methodological considerations unnecessarily complex and loaded with too many things. But what it does in more simple terms is that it opens up for seeing situations of design and use as sites where ethnographic inquiry can be performed as inseparable from and as co-constituting participatory design. Extending Redström's conceptualisation with an analytical ethnographic dimension opens up for the embodiment of ethnographic inquiry and prospective enactment of theoretical concepts such as "diagnostic agent" or "homework". So what felt as a strange merge of

ethnographic analysis on situations of participatory design when writing paper 2, now works productively to suggest the third proposition (a similar argument is further developed in Halse, 2008):

Proposition 3: Participatory design as ethnographic practice

I suggest considering participatory design – its methods, its tools and techniques as an approach to doing ethnography.

Design research

Now, engaged in methodological experiments of integrating participatory prototyping with ethnography, it was important for us to keep a process of design-by-doing while intellectually and pragmatically refining our methodology. Thinking about participatory design *as* a form of ethnographic practice, opened for the idea ethnographic inquiry could be proactively enacted through design interventions with the prototype. As a move away from rational and realist approach of action research, we looked in to research that is close to the traditional discipline of Design and that engages philosophically with it. In the following, I will therefore introduce some of the main lines of discourses on methodological issues surrounding the idea of designing while (ethnographically) researching.

The relationship between design and science has its roots in the ‘design methods movement’ of the early 1960s where aspirations to ‘scientise’ design resurfaced on the Conference on Design Methods held in London in 1962. Earlier, in the 1920s the methods and rhetoric of the modern movement was successful, for example seen in the work of the architect Le Corbusier who wrote about (and architected) the functionalistic and objectively-designed house as a ‘machine for the living’ (Cross, 2006, p. 119). The use of technology and the values of objectivity and rationality were in the sixties imported from science as a way to develop a method that could overcome human and environmental problems, which politics and economics could not. The scientific and rationalistic approach to design culminated in 1969 with Herbert Simon’s (1996) call for a *science of the artificial* to develop at universities. Design methodology continued to develop in the 1970s, especially in engineering and in branches of industrial design and the proliferation of this movement can be seen with the arrival of new journals of design research, theory and methodology; e.g. *Design Studies* in 1979, *Design issues* in 1984 and *Languages of Design* in 1993.

The advent of design research conferences and journals has increased the urgency on discourses, which further develops design epistemology, ontology and methodology towards the establishment of a mature discipline. Design research today is a highly eclectic and interdisciplinary field of study nonetheless its philosophical grounding is positioned in relation to existing research traditions (such as the natural sciences) or proposed in disarray to existing philosophical underpinnings by arguably having its own distinct ways of knowing and practicing (such as in the art world). To begin with, I was very inspired by Nigel Cross’ and others ambition of portraying design as a distinct discipline with its own “designerly ways of knowing” and the idea, that there is a distinct “designerly form of activity” that separates ‘designing’ from more established scientific and scholarly activities (Cross, 2006; Krippendorff, Klaus, 2007).

Designerly Ways of Knowing

Cross makes a call for design research to continue developing its own intellectual field and to “*avoid swamping our design research with different cultures imported from either the sciences or the arts*” (Cross, 2007, p. 46). He alerts design researchers not to be seduced by “the lure of *Wissenschaft*” and turn away from “the lore of *Technik*” (Cross, 2006, p. 22) – or otherwise said, he suggests to develop a culture of designerly inquiry with its own inner coherence but not one that fails to connect between sub-disciplines of science and humanities. He explains this as a paradoxical task; to create “*an interdisciplinary discipline – design as a discipline, rather than design as a science.*” (ibid.). Design research should thus be concerned with the development of domain-independent approaches to theory and research in design where the underlying axiom is “*that there are forms of knowledge peculiar to the awareness and ability of a designer, independent of the different professional domains of design practice. Just as the other intellectual cultures in the sciences and the arts concentrate on the underlying forms of knowledge peculiar to the scientist or the artist, so we must concentrate on the ‘designerly’ ways of knowing, thinking and acting.*” (Cross, 2007, p. 46).

One way by which Cross differentiates design from other disciplines is in the way designers problem-solve. Designers synthesise as opposed to scientists who analyse. He argues that “*the designer is constrained to produce a practicable result within a specific time limit, whereas the scientist and scholar are both able and often required, to suspend their judgements and decisions until more is known – ‘further research is needed’ is always a justifiable conclusion for them*” (Cross, 2006, p. 23)²². Problems in design are widely recognised as ill-defined, ill-structured or ‘wicked’ (Rittel and Webber, 1984) and related to situations of uncertainty and instability or phenomena that resist formalisation and demand a solution-driven strategy, as opposed to problem-driven. In response, the designer moves rapidly to devising solution conjectures where problems are understood mostly in relation to the ideas of their solution – they are partial structures and they ‘co-evolve’ by oscillating between the two. Quick responses to limited information, introduction of proposals and making priorities early on is foundational to designers’ strategies. Successful design behaviour is therefore based on adequate ‘problem scoping’ where targeted information gathering and

²² In his book Cross (2006) often talk about “the designer” in singular form and about all people having an inherent, natural intelligence of “design ability”. He frames many of his arguments under the label “design thinking” which denotes a particular individualistic cognitive view on what it means to design. Although subscribing to Cross overall endeavor many of his framings are very different from what I would like to argue with this thesis: No one person ever designs anything alone. Quite on the contrary, designing is more about *doing* than about *thinking*; it is more about getting equipped with the right tools by situating oneself in a generative network of people and things than about having some special design ability; it is more about aligning and making actors interested and cooperative than about trying, alone, to become ‘the designer’.

prioritising criteria are considered generative moves²³. Setting goals, but changing them according to developments in the process, are inherent to design activity. Cross explains that frequent shifts of attention or in mode of activity is highly related with the overall quality of design concepts produced. Good designers share the ability of making quick shifts between gathering information, generating ideas and modelling. Producing successful design concepts thus requires a process where the designer alternates rapidly in shifts of attention between different aspects of their task or between different modes of activity (Cross, 2006, p. 111).

In a process of co-evolving problem and solution, modelling becomes a necessary technique. In Cross words, modelling is ‘the language of design’ (Cross, 2007, p. 47). Traditional models are sketches and drawings, which support the designer to promote the recognition of emergent features and properties of a design concept. Drawing and sketching serves discovery and exploration but also re-construction of problems and solutions. The techniques are characteristic to ‘design thinking’ (ibid., p. 58) and underscores the reflective nature of designing, that of co-articulating problems and solutions and thus coincides with Schön’s (1983) argument of design as a ‘reflective conversation with the situation’. Cross makes the analogy, that by sketching, the designer engages in a dialogue with the situation in similar ways as writing helps researchers to explore and resolve thoughts – to reason.

Another proponent of a distinct designerly approach, Klaus Krippendorff (2007), constructs his argument on design research being a contradiction in terms – an oxymoron. He compares and contrasts what researchers in natural science do with what designers do: *“researchers are concerned with the truth of their propositions, established by observational evidence”; “Scientific researchers seek knowledge for its own sake, value-free, and without regard to their utility”; “Scientists are trained to be systematic and careful”; “Re-search involves sorting, re-arranging, tabulating, weighting and comparing data”.*

On the contrary: *“Designers invent or conceive possible futures, including its artefacts”; “Designers experiment with what is variable or could be changed” and “...define a space for possible actions, a design space”; “Designers make proposals” and “... work out realistic paths, plans to proceed towards desirable futures”; “Designers participate in stakeholder networks”; “For designers, success means enrolling stakeholders into the project of their design”.*

²³ In the summer 2008 Jonas Moll and I met with two designers from the Health group at IDEO in Palo Alto on our way to the CSCW08 conference in San Diego. They made it clear to us that an essential part of their approach was to find and articulate ‘seeds’ (ideas that relates problem and solution) early on in the initial stages of the project. These seeds then direct the design activities and by selection, the design team, over the course of the project, narrow down and prioritize to work on just a few seeds. This idea of ‘seeds’ surfaced many times in our discussions and became, in some way, implicitly installed in our approach and product.

According to Krippendorff, design is an *undiscipline*: “one that should be able to question anything and be allowed to try everything – provided its products are useful, work, and benefit others” (Krippendorff, Klaus, 2007, p. 74). Designers need to question prevailing ontological beliefs by not being afraid of undermining common convictions. Such inquiries require interaction with people, not more observations, Krippendorff argues. He draws dividing lines by arguing that “[s]cience articulates the constructions that worked so far. Design articulates constructions that might work in the future – but not without human intervention.” (ibid., p. 79). In this way Krippendorff emphasises the differences between design and research in terms of having a distinct temporal focus: “scientific theories are based only on what existed and could be observed prior to an analysis, design concerns artefacts that are not yet in use and could not have been observed in use, for which data are constitutively lacking, and experiences can at best be anticipated” (ibid., p. 72). Thus, to Krippendorff, design and research are incommensurable in conception – design research, as a subspecies of research, suppresses design because “[t]hey pursue unlike epistemologies” (ibid., p. 73).

Erik Stolterman (2008), who is an interaction design researcher in HCI, is similarly critical to the application of scientific methods when approaching, what he calls, *design complexity*. Design complexity is the subjective experiences a designer makes when faced with a design situation that offers potentially infinite and limitless sources of information, requirements, needs and so on. It is not possible for a designer to exhaustively explore all sources for potentially useful information and as a particular designerly response, according to Stolterman (2008, p. 57), the designer makes “all kinds of decisions and judgments, such as, how to frame the situation, who to listen to, what to pay attention to, what to dismiss, and how to explore, extract, recognise, and chose useful information from all of these potential sources”. He argues that despite science’s success in dealing with complexity, scientific methods are *not* transferable to deal with design complexity. He compares and contrasts design and science as two traditions of inquiry; science is concerned with truth, universality, generalisations, methodological rigor and reduces complexity by separating the phenomenon under study into manageable units (e.g. variables); design is concerned with the *non-universal* (the specific situation, user, functions), methodological rigor that is not measured by its successful process but on the *real use*, in a specific location and over time; design deals with complexity by considering the “whole” (including *emerging qualities* of the whole) and not only some parts as e.g. the designed object alone out of use.

Stolterman gives the example of distorted versions of and “sloppy” (“quick-and-dirty”) ethnography being the consequence of adapting and radically changing scientific methodological principles (“real ethnography”) to better suit design practice.

While Cross, Stolterman, and Krippendorff advocate for a design philosophy that is connected to, but epistemologically, ontologically and methodologically different from traditional research traditions, others suggest the fruitfulness of interdisciplinary approaches, as long as the research contribution could not have been done without design. Research-through-design is an approach that has gained particular interest and discussion, wherefore I will present this below.

Research-through-design

Despite attempts of bracketing design as a (un-)discipline, distinct from more established research traditions, there have been a growing number of publications where design activities and research are interwoven. Since Frayling (1993) suggested ‘research-through-design’ it has become an umbrella term uniting the methodological developments in the field. The design-based but interdisciplinary approach of research-through-design is widely discussed and there are many attempts of trying to stabilise it as a method particular to design research (see e.g. Bærenholdt et al., 2011; Cross, 2006; Frayling, 1993; Jonas, 2007; Koskinen et al., 2008; Mattelmäki, T. and Matthews, 2009; Sevaldson, 2010).

Yet, the methodological developments in the field are still immature but what has stabilised is the grouping of design research into three modes; research *into*, *through* and *for* design²⁴. Research ‘into’ or ‘about’ design treats designing as the object of study and traditionally operates from without (e.g. sociological studies of design or art history). Research ‘for’ design typically refers to e.g. user studies, market research or workplace studies, meant to inform activities of designing – “the researchers serve designers as “suppliers of knowledge”” (Jonas, 2007, p. 191). In research *through* design, design work becomes inseparable from research (Sevaldson, 2010) and consequently “... the contribution could not have been made in the absence of the design

²⁴ Cross (2006, 2007) introduces a different way of grouping the design-science relationship into four types of relationships. *Scientific design*, is one category of hybrid practice that refers to modern, industrialized design, which is based on scientific knowledge – distinct from pre-industrial, craft-oriented design. *Design science*, which since the beginning 00’s has been re-flowering in Information Systems (Hevner, A. R. et al., 2004), is rooted in a positivistic proposal of design as a rational, explicitly organized and systematic approach to design. *Science of design* is similar to research into design and means the study of the principles, practices and procedures of design (2007, p. 45). *Design as a discipline*, Cross derives from the constructivist paradigm where Schön challenged the positivistic approach of design science and proposed the idea of the reflective practicum – an epistemology of practice implicit in artistic and intuitive processes that (some) professionals employ in situations of uncertainty, instability and value conflict. He explains this as a reflective conversation with the material (Schön, 1983). See also Krippendorff (2006) and Bærenholdt et al. (2011).

project, process or artefact” (Mattelmäki, T. and Matthews, 2009, p. 4)²⁵. Sevaldson (2010) reviews the cross-sections and definitions and concepts used to address the relations between knowledge production and design work. He nuances research-through-design to include modes where design practice “serves to generate knowledge for an external agenda” (ibid., p. 13). To him, research *by* design practice is a mode that emphasises “the special inherent nature of design and designing as explorative and generative actions”, which is closer to the “unique core of design research”.

Research-through-design is also being introduced in the field of HCI where it is proposed as a promising, legitimate and complimentary approach to the dominating methods of scientific inquiry (behavioural science and computer science). Zimmerman et al. (2008; 2010) argue for a more formal version of the approach tying the construction of artefacts (by employing methods and processes from design practice) to the construction of theory: “researchers make prototypes, products, and models to codify their own understanding of a particular situation and to provide a concrete framing of the problem and a description of a proposed, preferred state” (2008, p. 42). Instead of limiting the research to an analysis of the present and the past, practicing research-through-design allows design researchers “to actively participate in intentionally constructing the future, in the form of *disciplined imagination*” (ibid., p. 43). Emergent social situations are triggered by technology and materials and the artefacts created “both reveal and become embodiments of possible futures” (ibid. p. 42). Through the construction of artefacts, researchers “make propositions of what could/should be”: “the artefact functions as a specific instantiation of a model – a theory – linking the current state to the proposed, preferred state.” (ibid., p. 44).

Zimmerman and Forlizzi (2008) propose two types of research-through-design: *philosophical* and *grounded*. In the philosophical approach researchers begin with a philosophical concept that they wish to investigate through a process of making. Examples include the work carried out at the Interaction Research Studio at Goldsmiths College where they e.g. “instantiate philosophical ideas about supporting ludic values in the form of an actual artefact” (Gaver, W. W. et al., 2004). The intention on what to study can come from the researchers’ personal or collective observations, from reflections on

²⁵The labels of the ‘for’, ‘through’, and ‘into’ typology are, nonetheless, also described in different ways. For example Frayling (1993) saw research-through-design as a rather unproblematic application of a practical experiment (such as developing new technology to address a problem) and communicating the results as in a report (such as in action research where a diary – a step-by-step documentation of a practical experiment – is used to generate the report). He saw research for design and art as the ‘thorny one’ (1993) where research is done within a design process and becomes part of the end product: “where the thinking is, so to speak, embodied in the artefact” (ibid., p. 5). Jonas (2007), on the other hand (who is critical to the typology), finds research *for* design less problematic and research *through* design as the theoretically challenging category where design and research are uneasy to separate.

‘what if’ or the motivation can come from previously articulated theory that the researchers want to “operationalise”. The *grounded* approach to doing research-through-design focuses on real-world problems and the motivation might come from sources such as research literature, current or on-going discourse and/or the problems might emerge from the design researchers’ own fieldwork: “Using a grounded approach, researchers move from fieldwork that details the messy complexity of the problematic situation to a process of ideation and iteration that forces them to codify their knowledge in a specific thing that has a specific, intentional outcome as a preferred state” (Zimmerman and Forlizzi, 2008, p. 43). To Zimmerman and Forlizzi (2008) the challenge for the research-through-design approach is to work on *not* creating a mismatch between the goal of theory and the goal of design practice. In this way they argue for the importance to connect the outcomes of designing with the focus of the theory development. Theory construction, then, becomes a design process involving sketching, critiquing, and refinement to address relations among all the elements.

Koskinen, Binder and Redström (2010) categorise according to the genealogy of research-through-design, practiced as extensions to the natural sciences, social sciences and to the art world. The *lab* approach focuses on causal mechanisms and builds on experimental psychology (natural sciences). It typically involves laboratory experiments with users using designed products aiming at devising valid claims to inform redesign (this kind of design research is widely developed in HCI). *Field* refers to approaches that are based on sociology and anthropology (social sciences) where in situ use is empirically studied and where design experiments become social objects, seamlessly integrated into the (typically qualitative) research contributions. Koskinen et al. acknowledges that in precursors (such as ethnomethodological studies in CSCW) studies of the work context were carried out to inform early stages of design, but in more recent work, research is integrated seamlessly into design. This integration is particularly strong in ‘field’ studies were a convergence with methods coming from the art world. As a third category, *gallery*, the workings of a gallery exhibition enable design researchers to place carefully designed objects in a showroom or in the field for presenting and involving people to experience (rather than only reflect). In post-critical approaches to design a somehow anti-scientific ethos is established and room is made for exploring non-utilitarian and ludic activities in combination with ‘field’ methods (see e.g. Gaver, W. W. et al., 2004).

Mattelmäki and Matthews (2009) turn towards the variety of features specific to the circumstances for making the contribution – and therefore away from the more general categories of research-through-design. They emphasise the diversity of ways in which design has been used to generate a research contribution and suggest “that research-through-design should not be seen as a method, but rather a family of heterogeneous approaches to design research

that only occasionally resemble each other” (ibid. p. 9). They argue that it is the intersections between a set of concerns including the program of the design experiments, the paradigm of the research tradition, the research questions, the audience, the evidence presented and the argument being constructed that makes the work a contribution. By six examples they argue for various relations between the *role of design* and the *type of contribution*; e.g. “design events as objects of analysis” (role of design) to present “how design can be organised” (type contribution), or, “products-in-use as components of experiment” to “identify methodological issues for research”.

It is evident, that since Frayling’s conception of research-through-design – almost two decades ago, design researchers have taken the approach in different directions many of which borrow the methodological foundation from classic research institutions and incorporate ideas from the art world and commercial design. Perhaps, most importantly, research that employs design practice as a means to inquire into some phenomenon is becoming an established mode of doing interdisciplinary research.

(Un)Productive tensions B

By turning to design research we had found a concept that could support our methodological questioning. With ‘research-through-design’ we were equipped with a legitimate approach but also with a thread of philosophical discourse that deals with the line of questioning, which we struggled with: *How can research and design be seamlessly integrated? Is it methodologically legitimate to do design-driven research? Is design and research practice ultimately different practices or in what ways is it fruitful to combine them?*

I bought into Cross, Krippendorff, Stolterman and others’ description of design work as an undiscipline (allowing all kinds of questioning as long as the outcome is useful and benefit others) and the idea of ‘designerly ways of knowing’ (independent forms of knowledge peculiar to the awareness and ability of a designer) where ‘design complexity’ is dealt with through quick shifts, co-evolving problem and solution. Yet, we disagreed with their claim that design work and social scientific work (research) pursue and is founded on unlike epistemologies. Quite the contrary, we subscribed to design research that treats research-through-design not as a method but as a family of heterogeneous approaches where research is integrated seamlessly into design (Koskinen et al., 2008; Mattelmäki, T. and Matthews, 2009). With these methodological assumptions we could, more comfortable, continue integrating participatory design and ethnographic work. This increased the space for intuition and prompt experimentation and left more room for design action when undertaking project activities. Informed of research-through-design we continued planning for activities to be included in the second action cycle, ‘Prototyping II’.

From duality to multiplicity [Paper 3]

Now, 18 months after the project began in 2008 we had moved through different stages of methodological application. Starting with a focus on developing a thorough analytical understanding of the healthcare network the project had now progressed through a participatory design process of designing, envisioning but also using two prototypic versions of what we began to call a personal health record (PHR) (see e.g. Kaelber et al., 2008). At this point, in spring 2010, we had succeeded in collaboratively identifying and translating insights into the design and development of a prototype and we had begun the facilitation of a process of design-in-use.

To be fair, the project had until now reproduced the traditional approaches found in CSCW and Participatory Design except; we were starting to realise the possibilities of having a prototype installed in use. From a distance, not much looks different from the ways in which design and ethnography have been mobilised on similar projects. Despite the intentions of experimenting with other ways of combining ethnography and design, the

project had not yet succeeded in materialising or articulating a different take on methodological convergence. The tools and artefacts created and used on the project are all more or less a reproduction of other similar research and development projects: Transcribed interviews, working papers, academic texts, post-it notes, collaborative documents, excel sheets, cardboard games, flyers, whiteboard webpage sketches, and working web-based prototypes. The same goes for the mobilised method and activities: participant observations, interviews, co-design sessions and workshops, concept mapping, and action research interventions, as well as writing research papers, reading the literature, making PowerPoint presentations, and giving conference talks. The level of heterogeneity of the participants involved in the project was, also, no longer that unusual; chronically ill heart patients with an ICD, relatives, secretaries, cardiologists, nurses, bioanalysts, and CSCW and Participatory Design researchers.

But as hinted above, there are emerging particularities of the project. One, was that a particular network, or collective, had started to materialise and another was the interdependent application of design interventions with working prototypes. The number of participants involved in the project (23 patients) had increased considerably and multiple artefacts and prototypes had been produced and put in effect. Initially the CITH project existed as ideas and conversations about project formation. Then it developed to become a joint research application and at a later point, it was a funded research and development project with a core group of eleven researchers, a website and flyers describing the project. Then twelve patients with an ICD and their related caregivers took part, and now, more than 23 patients and their relatives and clinicians have access to a fully working prototype of a personal health record.

This emergent network has so far achieved its dynamic by the application of research and design methods and the co-production of a long range of artefacts, which up until this point, could be localised mainly in university settings. However, with the deployment of the second version of the prototype, design and research had moved out of university boundaries. With the introduction of design interventions and working prototypes, co-production of design and research had become re-located and (to some extent) entangled with existing healthcare practices. As the thesis' third paper indicates, design interventions in medical consultations and in telemonitoring practices provided a space for the convergence of design and ethnographic research. After the action research study (paper 1) and the discovery of the potentiality of design interventions (paper 2) we reoriented our methodological position towards the more open-ended approach of research-through-design. In this way we could continue participatory design (in use) and continue experimenting with ways in which ethnography could be integrated. With research-through-design and the application of design interventions the

concern for dual inquiry was practically legitimised. Instead of having to perform an ideal method of producing ‘recoverable’ insights and define the prototype as a distinct functionalistic entity, research-through-design created space where we could at once produce insights relevant to design and knowledge relevant to ethnographic research.

As a way to frame and articulate our discussions and to support the project’s design research activities we decided to respond to the Nordic Design Research Conference ‘11 call. The result is paper 3 in the thesis. It is a collaborative achievement between Jonas Moll, Joachim Halse (associate professor at the Danish Design School) and I. The empirical material of the paper stretches in to the development and use of v. 3.0 of the prototype and is included in this section of the synopsis to present the transformations that occurred through the discussions we engaged in when applying design interventions – initially framed as research-through-design.

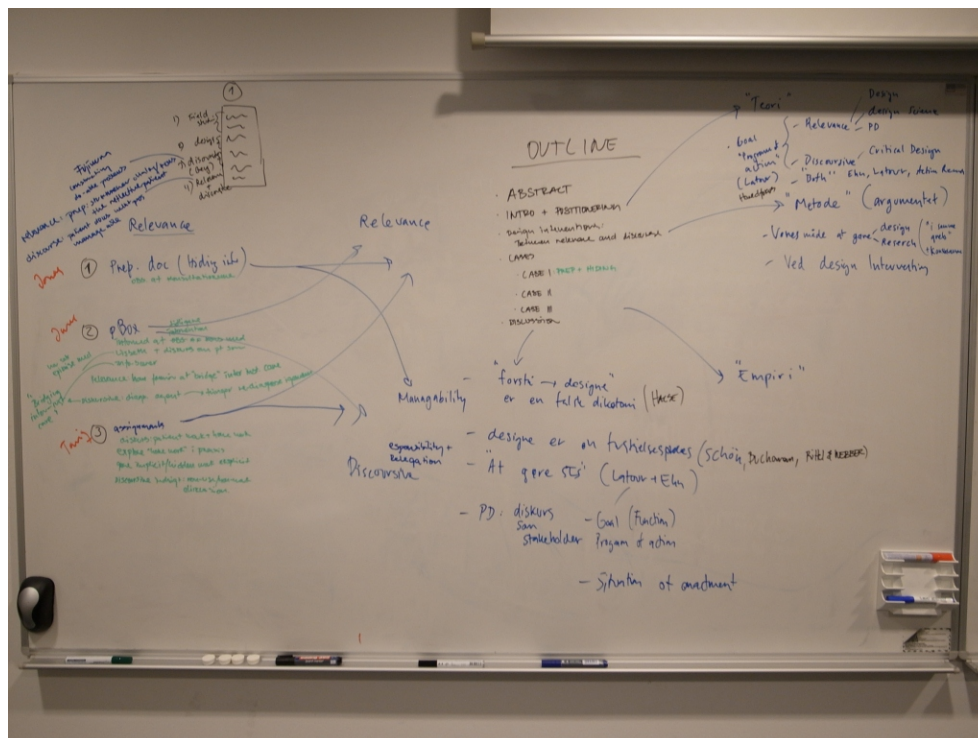
The contribution of the paper includes its empirical examples and the suggestion to ways in which ethnographic practice and participatory design can be engaged in *one move* through the application of design interventions with working prototypes. The paper can be said to have gone through three major iterations. In the following, I will use these iterations to illustrate the main point of the tension argued for in this section; that by making method assemblages of ethnographic research and participatory design, it is not only ‘research’ and ‘design’ practices that are engaged, it is also the involved patients and clinicians. This can be understood as acknowledging design interventions as a strategy of multiple becoming as opposed to a strategy of dual inquiry.

First iteration

The first iteration of the paper carried the title; “Getting a Design (Research) Tool to Work: Design Interventions in Healthcare” and was inspired by Marc Berg’s (1997) work on the scientific rationales performed in the development of (post war) medical technologies (see also Mol, 2008). Berg’s analysis highlights the conflicting encounters, or tensions, coming out the sciences’ rationalistic and formalised models of decision-support and the negotiations and disciplining of medical practice needed to get these tools to work. By reference to Berg’s analysis and chapter heading; “Getting a Tool to Work”, we wanted to suggest and discuss that the prototype and the work involved in making it a useful tool for design research and for patients and clinicians. However, since our discussions went in direction of the dual concerns of research-through-design, we changed the title to “Design Interventions as Dual Inquiry in Healthcare”. This was also done to clarify the paper’s conceptual contribution to design interventions (with working prototypes) as capable of encompassing the duality.

Second iteration

Now, settled on the concept of ‘dual inquiry’ we began to look for cases in our ‘empirical catalogue’ of design interventions. But we also began to look for future occasions where we could perform ‘dual inquiry’ and in this way produce empirical material for the paper. It was important for us to make the analytical frame of research-through-design clear and understandable in writing and to achieve this we discussed selected empirical cases in terms of how dual inquiry could be accommodated. This included two modes of inquiry; one that is design-led and performs questions relevant to the involved patients and clinicians, and a second, which performs an analytical and discursive interest relevant to an audience interested in ethnographic insights from healthcare technology development. Using this frame, we mapped cases on a continuum with two poles; “relevance” and “discursive”. We arranged three cases to illustrate how features of the prototype could be designed to embody, and by design interventions, inquire in to a) features relevant to patients and clinicians, b) features relevant to questioning and performing ethnographic concepts, and c) features that were intentionally designed to embody both a) and b). We called this a strategy of dual inquiry i.e. research-through-design.



Screenshot of whiteboard, where 3 cases are sketched on a continuum of relevance and discursive.

Case1. One case was meant to illustrate how a designed feature in the prototype; “Preparing for a medical consultation” was created with the immediate purpose of questioning while designing to support communication

between patients and cardiologists. In early fieldwork studies we found that patients brought questions with them to medical consultations and that cardiologists spent time before and during the meeting, ‘digging’ out actionable patient experiences. The prototype feature (webpage with text fields, check boxes, etc.) has been iteratively developed since the first version of the prototype through co-design sessions and co-design workshops and lately in design interventions with the prototype v. 2.0. It originated as a feature co-designed to support patient-cardiologist communication. However, as we wanted to illustrate, when installed and enacted in design interventions, the empirical material makes it possible to critically reflect and engage discourses on the logic of healthcare technology design. In this way, the feature, mobilised in design interventions, have the dual capacity of querying into the relevance of the design features while questioning the rationale of the design, possibly discussed along Berg’s (1997) concept of making patients “manageable” to clinicians.

Case 2. A second case was included to suggest more proactive ways of engaging in ethnographic research, while designing. In design research sessions we sketched a feature that would enable clinicians to give patients assignments or ‘homework’ (Grøn et al., 2008), which is an ethnographic concept. By installing this new feature in the prototype and by promoting its use in design interventions we made it possible to prospectively, as opposed to retrospectively, enact ethnographic categories such as “invisible work” and “diagnostic agency” (Oudshoorn, N, 2008), as well as ‘homework’²⁶. This feature, as a translation and reference to distant discourses, would then (possibly) travel and be instantiated as critical inquiry in design interventions. Yet, at the same time it would provide a means for experimenting with new ways of clinician-patient collaboration. By design interventions and the prototype in use, it was made possible to involve patients and clinicians in cooperative design experiments that proactively engage ethnographic discourses on socio-technical transformations in healthcare.

Case 3. In a third case, we created a design concept called ‘pBox’ (document handling), as a combined response to insights from design interventions and a paper presented at the Ethnographic Praxis in Industry Conference ’08 in Copenhagen. With this case we wanted to suggest how dual sources of interest could translate, materialise and become performative questions in design interventions. Unruh and Pratt (2008) motivate their study of ‘invisible patient work’ and make a call for CSCW to improve healthcare through patient-centred research and design. They conceptualise patient work as “bridging inter-institutional care”, “resolving inconsistent recommendations” and as “managing dependencies”. In one case they present a patient who becomes “a

²⁶ This case is also included in paper 5

de-facto information courier shuttling medical information from one institution to another” (Unruh and Pratt, p. 44).

Patients, who work to achieve continuity of care, were similarly present in our work. In one design intervention I followed a patient to her first medical consultation after her ICD implantation at the Heart Centre. She had managed to get a copy of the discharge letter and when she arrived at the hospital, she gave it to the nurse who did the preliminary examinations. The discharge letter was then copied and placed in the paper version of the medical record, which was forwarded along with the results from the examinations. When Lone (the patient) and I enter the consultation office, the cardiologist, at one point, says: *“We have received the discharge letter from the Heart Centre, which is very helpful...”* (Fieldwork notes, May 2010). Lone interrupts and explains that she was the one carrying the document along. In co-design workshops and co-design sessions in patient homes and in other design interventions we learned that a large part of patient work involves information management. Currently, this means paper work and the practical handling of healthcare documents. Many patients use document binders, notice boards in the kitchen and work desks and computers to store and organise documents from various healthcare institutions. They actively become information couriers as the case of Lone exemplifies and ask for copies of e.g. blood test results, extended transcripts from ICD telemonitoring, or official hospital statements to manage insurance cases. In sum, the management of healthcare documents permeate both the discourses on patient work and the lived reality of patients participating on the project. Managing healthcare documents is both a theorised object in academic discourses and a potential design challenge relevant for the participants of the CITH project. With double intentions we sketched and conceptualised a feature in the prototype called ‘pBox’ (i.e. the patients document box). This would let us install and perform dual inquiries of design and ethnographic research on patient work.

So, there we were well in to discussions and making cases available to construct an argument in the frame of research-thought-design to contribute to the Nordic Design Research Conference. The production of the paper progressed and we were doing what we could to articulate and make clear how we, in three cases, performed “design interventions as dual inquiry in healthcare”.

Third iteration

What happened was that, similar to the work on writing up the action research study for the IJMI special issue, the empirical and the theoretical frame collided in what could again be called (un)productive tensions. After carrying out a number of design interventions with the features, just described, we worked on writing up “the dual inquiry” in simple terms. This involved creating actual questions and concrete describable answers that could be related to either

“relevant for design of the prototype” or “relevant for academic discourses on patient work”. According to the theoretical frame, we treated the questions and answers separate in the hope that it would make a more convincing argument. However, this was more complicated than anticipated. For example, in writing up the first case we had difficulties constructing insights from analysing the unfolding design interventions that would showcase two clear and convincing insights; one relevant for concrete design action and one relevant for academic discourses. Among various alternatives we discussed an outcome of design interventions where patients prepared for medical consultations and remote telemonitoring by using the prototype feature and by selecting medical categories to indicate symptom experiences; e.g. “shortness of breath, under high physical activity” or “near faint, under high physical activity.” These categories of symptom experiences were designed to correspond to a medical heart failure classification thus making patient-cardiologist communication effective and, importantly, actionable for cardiologists. What we found from interventions and workshops was that cardiologists needed to know in what situations, at what time of the day, and to what degree these symptoms were experienced; “under high physical activity” was not effectively actionable in remote follow-ups. We found it useful to discuss this analytically using Berg’s (1997) concept of the design rationale of making patients “manageable” to cardiologists.

So, to devise answers for the two lines of inquiry we reached the following. In terms of insights relevant to design, we discussed that a solution could be to extend the checkbox-categories with neighbouring text fields and write something like; “please describe the situation, the time of day and the degree to which you experience it”. And, in terms of discursive insights, these findings could serve as a discussion on the ways in which the prototype participates in making patients “manageable” for cardiologists (Berg, 1997).

However, there we had the problem again. The two lines of reasoning, one backing the insights for concrete design action and the other backing the discursive insights, did not stand-alone. They depended on each other. Being loyal to our intentions of installing the feature in the first place, means that Berg and his analytical apparatus becomes applicable only as a consequence of the possibility for patients and cardiologists to communicate symptom experiences using the prototype. That is, no design experimentation with medical categories if there was no prototype making patients “manageable”. The same goes for the design-insights. Having exposed the checkboxes and the text fields to Berg’s “rationalisation of medical work” meant that we – in our analytical work, had already attached a critical understanding of what the checkboxes and text fields do. Despite our attempts to keep them analytically separate, they were interdependent through the work carried out in our design research practice. Our ‘research-through-design’ approach was, in realistic

terms, making entanglements of design and critical analysis – not one and the other but both at the same time.

Nonetheless, we proceeded to impose the split between the two lines of inquiry to make clear and convincing cases – although we felt something was not all right. Then, after a number of meetings and a paper that was almost complete, Joachim pointed out something quite revolutionary from our discussions. He challenged the foundational idea of having a strategy of ‘dual inquiry’ i.e. our operationalization of ‘research-through-design’. So far, we had already motivated the paper by distancing us from approaches that enact a disciplinary dichotomy, as in keeping design and ethnographic research as separate processes. This was in part a reaction to our experiences from the first cycles in the project (e.g. the referral study) and it was in part a way to position our learning from the action research study. Now, the question that Joachim was posing, was: *Are we not reproducing this dichotomy by suggesting ‘research-through-design’ as ‘dual inquiry’?* The answer was: *In many ways, Yes (unfortunately!).*

Certainly, we were interested in arguing ways wherein design and ethnography can benefit each other. But the question is moreover, when engaging design interventions with working prototypes and participants in healthcare; *are we, then, simply raising questions relevant to ‘research’ and ‘design’?; are design research methods just about creating knowledge and innovative technologies – or, are design research methods about creating new socio-technical configurations and, in turn, new ways of conceiving the world? Should research-through-design, not, be conceived as performing something more than a duality – but instead as opening up for multiplicity in being, knowing, and practicing healthcare?*

What Joachim suggested, was to rethink the philosophical model, which we were well into (re)producing. Framing design interventions as a strategy of dual inquiry treats the integration of design and ethnographic research as operating by the realist logic of ‘inquiry’ i.e. formulating questions and searching for answers. Although we did indeed engage in inquiry by crafting socio-material questions, the way we had shaped the cases evoked the idea that the prototype and its features could exist unrelated to the answers it participated in producing. In this way our framing installs a positivist episteme, just as in the action research study. However, as I have discussed above, this is not our intention – we subscribe to an epistemology where knowledge is very much situated, relational and emergent. But by making the separation of inquiry “relevant for design” and inquiry “relevant for ethnographic discourse” the disciplinary dichotomy is, again, reinstalled. Ultimately, Joachim encouraged that if we really wanted to dissolve the boundaries between design and research it would be beneficial to think of research-through-design, not (only) as knowledge productive i.e. methods capable of providing access to certain kind of answers, but moreover as socio-materially performative i.e.

where methods are positioned to co-produce phenomena and where subjects and objects becomes in and through their performed relations.

The consequence of rethinking our argument in a performative ontology had ramifying consequences for our work on the paper but also for the following design research activities and the thesis as a whole. As presented in the paper 3 and in Part 3.0 of the thesis, reading Mol's (2008) *The Body Multiple* and re-reading Law's (2004) *After Method* and Latour and Woolgar's (1986) *Laboratory Life* provided for a much more productive and realistic reworking of integrative experiments with participatory design and ethnography. To readers, who are unfamiliar with what is sometimes referred to as the posthuman or the performative ontological turn (Barry et al., 2008), some main influences will be presented below.

The outcome of rethinking design interventions in a performative framing, is best illustrated by the paper itself. But what it did to our discussions and the subsequent design interventions was to restore the tensions, which our strategy of dual inquiry had triggered. Thinking and doing design interventions in a performative and posthuman framing dissolves many of the unproductive tensions that we had struggled with. It becomes foundational for turning away from evoking disciplinary dichotomies and instead see 'research' and 'design' as mutually constitutive in situations of experimentation with the prototype. Research-through-design and our suggestion of a 'strategy of dual inquiry' tend to recall a logic of "what knowledge is produced" or "which insights, relevant to design and research are made". Employing Mol's (2008) empirical philosophy of 'multiplicity' and Law's method assemblage (2004) enable us to suggest:

"design interventions as a strategy of multiple becomings, wherein assemblages of patients, health professionals, diseases, information technology, prototypes, and design researchers together perform shifts between promoting new practical design solutions and raising novel questions on the socio-material complexities of healthcare" (Andersen et al., 2011, p. 1)

What is important, is that this ontological turn does not render our carefully crafted questions or participatory experiments with the prototype less relevant, meaningful or philosophically 'legitimate' – quite the contrary, terms such as 'enactment' and 'method assemblages' make our argument much more realistic or true to the situations unfolding. The philosophical tensions, that I have accounted for in great detail in this section, enable me to make a fourth proposition.

Proposition 4: From duality to multiplicity

I suggest employing design interventions, not as a strategy of dual inquiry, but moreover as a strategy of multiple becomings.

Practicalities: Getting a (design research) tool to work [Paper 4]

Ever since we installed Diary (v. 1.0 of the prototype) there has been a whole other category of (un)productive tensions involved in making design interventions with working prototypes and participating patients and clinicians. Methodological questions that signify our initial debates include the seemingly absurd questions such as “*are we doing ethnographic research, now? Or, are we designing?*” However, as presented above, these reflexive discussions turned out to be rather productive for our philosophical investigations. In this section I will bring forward the last of the (un)productive tensions included in the thesis. Below I will present how discussions, with much urgency, developed into a workshop on the ‘practicalities’ of prototyping at the Participatory Design Conference in 2010 (Andersen, Moll, et al., 2010) and later, after several revisions, in to a manuscript for a special issue of *CoDesign*. In this section I will present the main argument from paper 4.

Ever since we chose to engage participatory design activities, a host of practical activities began to demand attention. Especially after introducing cooperative prototyping and installing the first prototype in use, a long range of unavoidable ‘background’ work appeared; all that concrete, practical work, which traditionally is treated as somehow insignificant to methodological and epistemological discussions²⁷ entered as activities that were necessary for the becoming of the project. Very much inspired by Pedersen (2007) who engages in what could be termed methodological inversion, we started to see, realistically, what *practical* achievement it is to do participatory design. By employing thinking from Science and Technology Studies and Actor-Network Theory (which I shall present below in Part 3.0) Pedersen opens up black boxes of participatory design and workplace studies to make the critical remark, that the protocols of research and design are not innocent. However, Pedersen encourages us to take serious the long traces of negotiation, the work of interesting participants and, in particular, “the concrete practicalities” that influence the conditions for the possibility of making ‘participation’ and doing ‘co-design’ (ibid. p. 132): “*Still, I suggest that it should sensitize to the fact that as researchers we are not just making studies of and designing for and with practitioners – we are very much practitioners ourselves [...] we are not just involved in managing two differences as the protocols suggests [use and design, and present and future]; we are involved in managing a third difference – that between research and the rest*”.

This third category of aligning *research* and the growing amounts of work, which is typically not considered as research, was so overwhelming that we at

²⁷ By the concept of ‘practicalities’ (Pedersen, 2007), we engage in unboxing this very much overlooked category in design research work. Practicalities are most rarely considered ‘research problems’ – or perhaps more to the point; Posthuman performativity theory has not reached far enough. As anonymous reviewers of earlier version of the paper write: “*To conclude, I do not believe that these problems reported are research problems*” or “*i.e. it is not a research paper. All the practicalities that mentioned in the paper could be avoided by other design methodologies such as ethnography.*”

times considered the mundane practicalities as defining what is ‘research’, ‘co-design’, and ‘participation’. In line with the discussions above of methodological tensions, it was impossible to disregard all the time, activities and tools needed for the project of design and research to progress; emailing, calling, networking, promoting, negotiating, and interesting participants (to mention a few) came to be ‘the doing’ of participatory design and ethnographic research. It was straightforward; we felt that our roles had changed to become project management assistants, project secretaries, IT supporters or system integrators. Not that these roles are insignificant but moreover that they are typically treated as trivial or secondary to design research contributions. Along with the whole lot of ad hoc activities came a myriad of homemade tools and artefacts – all created to support this work; collaborative documents and excel sheets, flyers, help videos, a project website, a Skype-in answering machine, written consent forms, questionnaires, post-it notes, etc.

For example, to accomplish a 15 minutes design intervention with the prototype in a medical consultation meant to mobilise a long trace of negotiation, backstage activities and tailor-made tools. First of all we had to make patients and cardiologists interested in ‘participation’ and promote use and ‘co-design’ of the prototype. Activities that proved to be conditioning for the design intervention include the identification, contacting and enrolment of both patients and cardiologists. This seemed straightforward because cardiologists were already participating in the project and potential patients should then be in close range of the project. But this was far from the case.

As it turned out, we had to try different strategies before we succeeded in having the setup needed to carry out the first design intervention. Initially we had a dialogue (email, telephone and meetings) with cardiologists on the project and agreed that they would keep an eye open for potential candidates to contact. This provided contact information on just a few patients and as criteria for participation developed we had to devise other ways of increasing the reach for potential patients. Criteria that made it difficult to identify appropriate candidates were; patients had to accept and be interested in participating, they had to live in ‘bike-range’ from the university, be able to use a computer and the internet, and have a scheduled medical consultation in the near future. To support this we created flyers describing the project, created a webpage on the project website as a call for participants and included questions in a large scale paper-based questionnaire study that would select out a list of patients to contact. Then we took time to call or email patients and plan for internal project management meetings to discuss progress in terms of enrolling participants. We arranged to call secretaries each week to get a list of patients who were scheduled for an ICD implant in the near future, and so on.

These activities, in turn, led to the creation of various spreadsheets where we in cooperation could annotate who have talked with whom, about what, the

patients immediate comments on their interest in participating, when they would have their next medical consultation etc. Then we would need to coordinate with the cardiologist and the secretary at the local hospital, to make sure that there was not another cardiologist appointed to the meeting. After acceptance to participate, we would snail-mail step-by-step guides on how to use the feature of preparing for a meeting. We eventually created guide-videos that could be viewed and listened to from within the prototype and sometimes we would call or visit patients in their home, the day before the meeting, to help them use the prototype (as well as engage them in re-design).

As we suggest in the paper 4, design interventions on the project are made possible through hard proactive work and the mobilisation of a long range of tailor-made tools and technologies. Informed by Pedersen (2007), actor-network theory and science and technology studies, we open up the black boxes of concepts like co-design and participation to argue; ‘Co-design’-ready health professionals and patients are not just out there a priori to the project (a comment made by Pedersen in a paper review meeting). Instead, they need to be performed in, by, and through ‘invisible’ work and a myriad of helpful tools and techniques.

As with the propositions I have put forward above, this fifth and last proposition has appeared as a result of what at the time felt unproductive in terms of philosophically getting along. The productiveness of the many discussions with Troels Mønsted, Jonas Moll and Jens Pedersen, and the participatory prototyping process’ demands for making practical solutions and tailor-made tools, enable me to make a fifth proposition.

Proposition 5: Practicalities of participatory prototyping

I suggest taking serious the practicalities of design interventions with working prototypes and moreover to engage proactively and creatively with whatever the process demands.

PART 3.0

In late September 2010, six months after the second version of the prototype was launched, v. 3.0 of the prototype was ready to be introduced to the participating patients and health professionals. At this point in time, the project was well in to an explorative process of method experimentation and philosophical transformation. At the same time the process of applying working prototypes and conducting design interventions was maturing. The first and the second version of the prototype were installed by inviting participants to launch workshops. But with the third version of the prototype we wanted to grow the number of participants for several reasons. One reason was that we wanted to involve patients who had never seen, used or co-designed features of the prototype, because in this way, we could begin shaping the prototype from being mostly exploratory towards being closer to a product that could be marketed. Instead of just being an invention, with more patients using it, it could become an innovation. Another reason was that we wanted to trial new features that would benefit from a larger number of users (Network and Messages).

However, before describing v. 3.0, its features, and what took place after installing it in practice, I need to make an introduction to the philosophical reorientation that was happening. Turning to the field of Science and Technology Studies (STS) and Actor-Network Theory (ANT) affected our design research activities in radical ways. As I will show in the following, it established grounds for not only employing STS and ANT in retrospective analysis, but moreover for experimenting with the performative and generative potential in design (this argument has been partially introduced by paper 3).

Below, I present some of the main sources of inspiration from work in STS and ANT and as a response to its influence on our work, I will re-position the thesis in relation to novel work that explores the boundaries between design and STS. In this last part of the project, and correspondingly last part of the thesis, I will therefore attempt to situate our latest design research work in relation to emergent discourses on STS-Design method. On this positioning, I make the last case by bringing in a complimenting paper 5 and an additional case, which I call 'Prototyping patient 2.0' (Similar to the title of our abstract on the EASST 2010 conference).

Posthuman performativity

While scholars in the beginning 1980's met and formed research alliances under the conference acronyms of CHI, CSCW, and PDC (first conference in 1990²⁸), a small group of sociologists interested in the relationships between science, technology, and society gathered in Austria in 1982 for the first European Association for the Study of Science and Technology (EASST) (Bijker et al., 1987). This conference was and still is, just one mark of what has come to be known as a highly interdisciplinary field of Science-Technology-Society studies or STS. Thomas Kuhn's (1996) influential work, *The Structure of Scientific Revolutions* signifies the 1960's alliance of history and the philosophy of science and the first attempts to bring in other factors (sociology and psychology) in the understanding of natural scientific methodology. Other movements such as feminist studies and sociologists of science were activists in the 1970s toward a break with the dominating philosophical ideals of objectivity and science as apolitical. One of the tenets in the becoming of the STS field, was that scientific practice, like all other kinds of practices, is permeated by social activities where knowledge is inseparable from situated action.

Realities are made

One of the most influential books in what has been termed science studies, is Latour and Woolgar's *Laboratory Life* (Latour and Woolgar, 1986). It is an ethnographic account from two years of fieldwork in the late seventies' Sal Institute research laboratory. By way of anthropology, Latour (with a poor English) and Woolgar's visit the laboratory unfamiliar with science and what goes on at such sites. They study the "tribe of scientists" (ibid., p. 17) as any other tribe and come to argue that the scientists similarly have culture and beliefs and importantly; *practices*. The scientists' work, chats about everyday matters, and worry about the future but they moreover engage a particular set of instruments and expensive apparatus in their everyday practices. Being more or less constructivist, they argue that scientific knowledge is 'constructed' or 'produced' in the laboratory. It is important to note here that this is not the same as saying that the scientists construct scientific knowledge, but, and in favour of the authors' focus on materiality, it is actively created in practices that include a whole range of human and non-human participants. The physical stuff in the laboratory and the architectural layout with a chemistry section, physiology section, and places with desks and word processors – are all together inseparable parts of the material production of scientific facts. Besides people, then, materials also move around in the laboratory. In particular

²⁸ In 1985 in Aarhus, Denmark a conference on 'Computers and Democracy' was held as a follow-up to a decade of Scandinavian user centered design (Bjerknes et al., 1987). The first Participatory Design Conference was held in Seattle, Washington in 1990 (Greenbaum and Kyng, 1991).

different kinds of paper with specific text is produced, circulated and moved out of the laboratory. As it turns out, the major (material) product of the laboratory is *text*.

Latour and Woolgar then follow the paper and find working scientists sitting by their desks juxtaposing texts of different kinds. They observe that some texts, such as scientific articles and books, come from outside the laboratory while others are produced within the laboratory. And, it is the production of these latter kinds of texts that Latour and Woolgar unravel to show how a system of artefacts, often including machines, create graphs, numbers and other kinds of inscriptions. They call devices that make these traces *inscription devices*:

“An inscription device is any item of apparatus or particular configuration of such items which can transform a material substance into a figure or a diagram which is directly usable by one of the members of the office space.” (Latour and Woolgar, 1986, p. 51)

It is by the conceptualisation of inscription device, that it becomes possible to show how the materiality of the process gets deleted. The procedure might start with rats that would be sacrificed to make extracts, which would be placed in test tubes that then enter a machine such as a radiation detector. The machine then converts the extracts into an array of figures on a sheet of paper and it is these inscriptions that are said (or assumed) to have a direct relation to the original substance. Interestingly, what follows, is that the scientists no longer use the rat themselves or the substance to discuss what they have created but instead it is the curves and figures from the inscription device that gets manipulated and juxtaposed on the desks. By these steps, Latour and Woolgar emphasise how the prolonged and costly process of making the traces gets transformed and disappears into the background. This argument, that scientific facts are socio-materially constructed, amounts to the authors’ constructivist foundation, but they make an important extension to this point, as Law puts it:

“...particular realities are constructed by particular inscription devices and practices ... realities are being constructed. Not by people. But in the practices made possible by networks of elements that make up the inscription device – and the networks of elements within which that inscription device resides.” (Law, J., 2004, p. 21)

The argument here is that phenomena created in the knowledge production in the laboratory does not simply *depend* on certain material instrumentation, rather, the “phenomena *are thoroughly constituted* by the material setting of the laboratory.” (Latour and Woolgar, 1986, p. 64)

These modest assertions about the work of scientists carry a range of implications for the truths claims made in science and, as I will expand below, they become the first steps toward the shaping of actor-network theory (ANT). As presented in Latour and Woolgar's laboratory ethnography, it is the scientists' assumptions that they discover realities that are 'out-there' and that the statements they make carry no traces of subjectivity. But, as we have seen, reality *is* what goes on in the production of scientific facts, which is a making of (new) relations from what was before non-traceable to what has come to be traceable. Relations of what did not yet exist are *made* to exist. Some fact in the shape of a statement is made to represent something as in one-to-one. The crucial point here is that, contrary to what is commonly held, the realities/truth claims/facts are *consequences* of scientific method rather than its *cause*. They are effects of particular socio-material translations of inscription. Before the apparatus is in place and certain activities unfold there are no facts. In short (and provokingly), realities are made: "*Reality is neither independent nor anterior to its apparatus of production.*" (Law, J., 2004, p. 32)

Heterogeneous collectives

Latour and Woolgar (1986) have shown that scientific facts come to be as a result of their relations with other entities. The product of scientific method is the outcome of a particular network of working scientists and machines – of human and non-human entities. The inclusion of materials, then, is foundational for how realities are made. This is different from traditional views on reality, such as Euro-American common-sense thinking, where dualisms (such as human and non-human, true and false, in-here and out-there) are stabilised principles. In short, the material as in the laboratory, is traditionally contributed no agency because it inappropriately distorts the logical truth claims. On the contrary, in actor-network theory or ANT the material is attributed agency. Non-humans are seen as being actor just as humans are actors. But not alone – they act according to their configuration. And therefore, humans as well as machines are simultaneously an entity (an individual) and a network (a collective) (Callon and Law, 1997). It is no longer possible to talk of the social without taking account of the material. The social is materially heterogeneous.

To make this point more clear I find it useful to reference Callon and Law's (1997) use of what they call magnificent studies of primates – of baboons. The reason is that baboons rarely make tools and therefore draw on somatic²⁹ resources when they interact and cooperate. The implication for the baboon society is this:

"[I]f you want to be leader in baboon society (a position generally occupied by big males) you cannot mobilize walls, rifles or social security numbers. You cannot send

²⁹ 'Somatic' in the merriam-webster dictionary: "of or relating to the wall of the body"

letters to your baboon colleagues. You have no secret police. All you have is your own body. If you want to be chief, you have to be there in person in order to reproduce your authority. Domination depends entirely on face-to-face confrontation. The use of the body. Or, perhaps, the use of someone else's body [...] the collective is built by naked bodies alone. No other materials are involved. There are no texts or artifacts, and no money circulates. The social glue is somatic and somatic alone." (Callon and Law, 1997, p. 186)

In baboon societies not many materials are being mobilised. But in human societies the situation is different. Tools and artefacts abound but not only as resources or constraints³⁰ or as passive and only active when mobilised by humans. The ANT-principle is, somehow counter-intuitive, that there is no difference between the person and the network of entities that acts. Ultimately, it is heterogeneous actor-networks, 'collectives', that act.

Performativity

ANT has a second principle that springs from the idea that the social is made up of relational materiality or hybrid (heterogeneous) collectives (Callon and Law, 1995). If entities achieve their form as a consequence of the relations in which they are located they necessarily are "*performed in, by, and through those relations*" (Law, J., 1999, p. 4). The second principle, then, has to do with *performativity*. When we recall the Salk Institute scientists' practices and how they make relations as part of their method it was crucial that they did this only in association with the laboratory network (equipment). This means that the facts they produce only come to exist as when they (the actor-network) act (together). The facts become only as an effect of the networked practices.

Law, who is one of creators of ANT, explains that the tension the term 'actor-network' embodies is *intentionally oxymoronic* (Law, J., 2004, p. 5). This tension lies between the centred 'actor' on the one hand and the decentred 'network' on the other. The implication of putting them together is that they come to constitute each other. The actor only is in relation to its network and the network only is in relation to its individual actors. They constitute each other. This is a contradictory of terms, it is oxymoronic, and no longer makes sense to understand them apart as stable entities. The actor-network is dynamic in essence and only exists when in action – when performed in some practice. Reality is a relational effect (Law, John and Urry, 2004, p. 395). And this is important to ANT. *Practices*, then, become centre of attention because it is in practices actor-networks are performed.

The implications of performativity reaches further than how to understand certain phenomena. It has consequences for research methodologies themselves. Not only for (natural) scientists in the laboratory

³⁰ As layed out in Giddens' Theory of Structuration (Giddens, 1986)

but just as much for the social scientists who study them or for design researchers for that matter. Social science methods therefore also produce the realities they describe (Law, J., 2004). Methods have effects because it helps to bring what it discovers into being (Law, John and Urry, 2004, p. 393):

“However, if method is interactively performative, and helps to make realities, then the differences between research findings produced by different methods or in different research traditions have an alternative significance. No longer different perspectives on a single reality, they become instead the enactment of different realities. This is a strong claim, but very important. The shift is from epistemology (where what is known depends on perspective) to ontology (what is known is also being made differently). It is a shift that moves us from a single world to the idea that the world is multiply produced in diverse and contested social and material relations. The implication is that there is no single ‘world’.” (Law, John and Urry, 2004, p. 397)

Multiplicity and relational ontology

As Law and Urry (2004) articulate it in the quote above, it is a general project in STS (and ANT) to suggest a shift in the mode in which knowledge production is considered. This shift reconceives knowledge production from being a matter of epistemology (where what is known depends on perspective) to being a matter of ontology (what is known is also being made differently). Mol’s (2002) ‘The Body Multiple’ is a canonical text that explores this issue, namely how different practices enacts ‘knowledge’ in different ways. She calls this an exercise of “empirical philosophy”. Her ideas centre on the concepts of “multiplicity” and the management of “difference”. By an ethnography in healthcare, Mol makes the argument that the illness of atherosclerosis is not singular, but multiple. With this somehow paradoxical argument, she engages an ontological shift by empirically foregrounding how atherosclerosis *exists* only in relation to practices. This stands in contrast to the modernist and normative understanding of an illness since atherosclerosis, then, can only be understood as relative to a situation or a specific site. It is no longer meaningful to speak of atherosclerosis without speaking of the socio-material practices that performs it. ‘Atherosclerosis’ is therefore not something universal and singular, as in medical scientific accounts, but multiple and enacted in different ways across various sites, with different bodies, and with various tools and technologies. It makes sense only to understand the illness as of ‘when’ and not as of ‘what’³¹. Mol’s philosophy becomes particularly clear, when she tells the story about a patient, Mrs Tilstra and her left lower leg:

*“In the consulting room something is *done*. It can be described as “pain in Mrs Tilstra’s left lower leg that begins on walking a short distance on flat ground and stops*

³¹ The much cited Leigh Star and Ruhleder (1996) article engages a similar framing by asking not what, but “when is an Infrastructure?”

*after rest.” This phenomenon goes by the medical name *intermittent claudication*. Whatever the condition of her body before she entered the consulting room, in ethnographic terms Mrs Tilstra did not have this disease before she visited a doctor. She didn’t enact it.” (Mol, 2002, p. 22)*

Mol argues here, that the diagnose of intermittent claudication is not enacted before Mrs Tilstra comes to the doctor’s office and before she answers the question of how far she can walk without pain³². It is in the doctor’s office, where all his equipment is available that they together do the diagnosis. And this goes on, because intermittent claudication is enacted in other ways in the laboratory where a myriad of artefacts and technologies together enact another version of intermittent claudication. The same in Mrs Tilstra’s home where Intermittent claudication is performed differently, and so on. Intermittent claudication is multiple.

Again, this is an ontological move since Mol is no longer interested in acquiring knowledge in an epistemological way, as a matter of creating true references but moreover she is concerned with knowledge as a matter of “manipulation”: *“The driving question is no longer “how to find the truth?” but “how are objects [or phenomena such as atherosclerosis and medication management] handled in practice?”*

³² To some extent, Mol’s argument that intermittent claudication emerges in relation to (situated) practices and the materials and tools available is very similar to one of Becker’s (1984) (Chicago School sociologist). He suggests thinking of art as when it has entered the collective activities related to the art world. For example, whether jazz is really music or photography is really art depends on its position or to use Mol’s philosophy; where it is enacted. Jazz is jazz when an audience listens to it in a jazz club and photography is fashion photography when exhibited and sold in important galleries and museums (ibid., p. 135.)

In(ter)ventive methods

As proponents of ANT suggest, all (social scientific) methods “*not only describe but help to produce the reality that they understand*” (Law, J., 2004, p. 5). Investigations of all kinds interfere with the world, and in some way or another, change is always the result. Methods are always political and performative. For these reasons, “*the issue, then, is not to seek disengagement but rather with how to engage*” (ibid. p. 7). Law calls for social scientist to acknowledge that intervention and engagement should be fundamental to methodological reflexivity and practice. The ANT project and the call for acknowledging the performativity of methods can be seen as the outcome of the deliberate turn to study the Western techno-scientific elite (as opposed to the traditional anthropologic visits to foreign and exotic sites).

Nonetheless, their (radical) re-formulation of social science philosophy have developed in tandem with what Latour calls a shift from “a matter of facts” to “a matter of concern” (Latour, 2005). In the early studies, such as Latour and Woolgar’s (1986), STS researchers were few and outnumbered and they approached their object of study as visitors, “strangers” or outsiders. Now, in light of their academic success, STS and ANT have expanded intensely and STS researchers are gradually becoming much more ‘entangled’ with their object of study (Woolgar et al., 2009). STS researchers are no longer just visitors and authors who provide critical analyses of some site or phenomena; they increasingly engage in *discussions* and *decisions* as opposed to previously where they were *invited* to sites of techno-science (Jensen, 2012). As Jensen reports, STS researchers have today managed to be invited (or invited themselves) further into technological, scientific, and public policy activities. They have taken on roles such as technology designers, market researchers, expert court witnesses, public-engagement consultants, and research-policy advisors.

For this reason and several others, discussions on more action-oriented or ‘interventionist’ modes of doing social scientific research has re-entered the discussions. A second reason can be ascribed to the broader ontological turn within the social sciences and the related philosophical orientation towards *performativity* and (posthumanist) *practices* as Law and others (Barry et al., 2008) signify.

A third reason can be ascribed to the intensifying demands for integration between science, society and economy (Barry et al., 2008). It is an existing trend to see national funding schemes prioritise interdisciplinarity and call for research that renders science accountable to society and forges a closer connection between science and innovation. In Denmark for example, programmes that support ‘user driven innovation’ and the strategic inclusion of sociologists and anthropologists on interdisciplinary research projects have

provided substantial funding (€55 million in 2007-2014 from where the project, CITH, I am reporting of is funded) (Halse, 2008; Jensen, 2012)³³.

A fourth reason could be attributed the success of the sociologists and anthropologists' engagement with technology development. Here I refer to the pioneering work of researchers that have shaped Participatory Design and CSCW. To these fields of research, accountability to society or workplaces and the involved participants is inscribed in their methodological foundation (see Part 1.0). 'Intervention' and 'engagement' is practically unavoidable. In fact, and as I have presented in Part 1.0 of the thesis, politics of (design) intervention and the nature of engaging participants have been the driving discourses in Participatory Design³⁴ (although in a more pragmatic and tools-technique oriented focus as opposed to a philosophical). Ethnography and the involvement with the IT industry is another major influence on the push for more interventionist social science. It developed, in particular, from the ethnomethodological studies of work and the interdisciplinary collaborations happened mostly in technology firms. However, this movement has continued and has been dispersed across a range of commercial and academic settings. This is evident with the arrival of the first EPIC Conference (Ethnographic Praxis in Industry) in 2005, which promotes the use of ethnographic investigations and principles in the study of human behaviour as they are applied in business settings (see also Cefkin, 2010).

Nonetheless, debates in STS on the relations between 'description' and 'intervention' are occurring. In many ways it resembles the age-old discourse in CSCW and, to some extent, Participatory Design – a debate discussing similar issues along the lines of 'analysis' and 'design', which this thesis is taking part in through paper 5. Some STS researchers suggest moving away from merely descriptive analyses of technology and apply a more active engagement and intervention as practiced in CSCW and Participatory Design (Hess, 2001). Berg (1998, p. 457) claims that *"the traffic remains mostly unidirectional: STS researchers venture into the lands of engineers, but the latter are not very interested in joining them on the return trip. To come full circle, actually to employ social theory in design, is a fascinating additional step"*. Berg acknowledges that descriptive analyses in CSCW, similar to the project of STS, show how the interrelation of the realms of technology and human work "lead to the emergence of new worlds". Yet, he criticises the way in which such analysis refrain from questioning the underlying dichotomy; *"the ontology and logic of the realms themselves remain unaffected"* (ibid. p. 473). However, he is very much sympathetic to the practical project of CSCW. He writes:

³³ The fact that design and innovation have become powerful figures in many Western countries' funding schemes make them natural subjects or objects for STS researchers to study.

³⁴ Kensing and Blomberg (1998) summarize three main issues that have dominated the discourse in the PD literature: (1) the politics of design, (2) the nature of participation, and (3) methods, tools and techniques for carrying out design projects. (see e.g. Kensing, Finn and Greenbaum, 2012; Schuler and Namioka, 1993)

*“Their [CSCW researchers] focus on this recursive relation between tool and practice led them to a new, original step: they construe design itself as a locus for political action. They practice *design as critique*: they explicitly attempt to transform a practice toward a preferred goal through the production and implementation of an artifact in which this goal is inscribed. This is a pragmatic activity, accepting the ongoing negotiations that constitute this path, and the impossibility of ever achieving a goal in any pure form. Design as critique is the attempt to achieve “social change” through rewriting preexisting relations in the durable form of a computer system, or a software package.” (Berg, 1998, p. 482)*

In this way, Berg argues that STS should look to CSCW and PD as ways of “doing politics” and for a substantive move to “materially refigure” the practices in question (ibid. p. 483); *“a critical position implies immersing oneself in the networks described and searching for what is or can be achieved by new interlockings of artifacts and human work”* (ibid.).

Other STS researchers reject the dichotomy between description and intervention and argue that STS has always been intervening. Vikkelsø (2007), for example, questions if the choice really is between action and politics on the one side, and passivity and neutrality on the other. She draws on a case where a researcher is asked by a manager to deliver *““prospective ANT” and thus moving from a retrospective description of socio-material translation processes to an active experimentation with the evolving relationships of people and technology in organizations in order to find a good solution for the hospital”* (ibid. p. 299). However (and slightly counter intuitive to her argument), as it turns out, the researcher finds herself in a dilemma of entering into the already formed organisational relationships where she had to either practically assist the manager in reaching his goals of resolving controversies or engage by making a more conventional ANT description. The researcher chose the latter. Vikkelsø uses this case to argue that, although an ANT analysis will not deliver anything that will easily settle such organisational controversies, a so-called retrospective actor-network analysis, if done properly, will produce performative effects and may open up windows of action. However, and this is interesting, a descriptive analysis has to be, *made usable*. Practical relevance, Vikkelsø proposes, can be achieved by translation:

“The practical and political implications do, however, not flow automatically from the analyses. Thick empirical descriptions are only read by extraordinarily interested readers. In order to interest other types of readers, detailed description of socio-material relationships—whether focused on strategies or multiplicities—must be translated into ‘executive summaries’ customized for specific audiences.” (ibid. 303)

Vikkelsø provides examples of ways in which “passive descriptions” could translate and interest others; SWOT (strengths, weaknesses,

opportunities, threats) analyses, executive summaries, public articles in newspapers and magazines.

Articulating this as a being a matter of intervention vs. description is perhaps, somewhat futile, as Jensen (2012) writes. As Vikkelsø does, he reformulates the key question about intervention to a concern of *how* the contributions from STS will combine with those of other participants in joint projects. The importance is not *if* STS analyses are action-oriented – because most people are in favour of intervention, or engagement, or of somewhat making a difference in the world – but rather *in what specific ways* engagement and intervention actually happens (see also Zuiderent-Jerak and Jensen, 2007).

As I have put forward already, the idea of such translation and analysis ‘made usable’ is of central concern to this thesis. By making a last case from our empirical work and by positioning this work in relation to forming trends of STS-design method entanglements, I present how we go full circle with method experiments of ethnography-design assemblages. That is, how we employ ethnography, not just by translation, but as ‘prospective analysis’ (borrowing from Vikkelsø, 2007).

STS-Design

In the following, I will focus on emerging interests of combining STS and design in new modes of doing research. I call these STS-design method assemblages, which moves away from what have been a tendency so far; social scientists treating design as a topic for research and designers treating social science as a resource for design.

While social science in general share a historical partnership with various fields of design research (see Part 1.0), it would be fair to say that contributions directed at experimenting with integration of STS and design research (and the art world) is mostly an emergent, yet, partially established movement. What is somehow different from earlier social-science-design engagements is that researchers from both sides are showing interest, at the same time, in each other’s practices and philosophical offerings. The outcomes can be seen as contributions to the fields from which they depart, but the outcomes can also be seen as transcending their origins. What I am particularly interested in foregrounding here is research that articulates a kind of interdisciplinarity that somehow points at new modes of research. Barry et al. (2008, p. 20) suggest this logic of interdisciplinarity as “*effecting ontological transformation in the objects and relations of research*”. This could be understood as research practices that embodies intentions of affecting change in the relations between ‘what is’ or ‘what can be studied’ and ‘the way it is studied’. Effecting ontological change is an “*orientation towards re-conceiving both the object(s) of research and the relations between subjects and objects*” (ibid., p. 25). This is not a simple matter but it is one model that will assist describing the directions of where research on the CITH project

has gone. However, first I need to present what kind of STS and design research engagements this thesis (Part 3.0) is (trying to become) positioned amongst – or at least relate to.



Picture from the EPIC'08 conference of an installation: *Physical Bar Charts*

But where to look if the research, which I want to engage, is emergent and only partially established? Well, conferences would be a good first place to look for what could be called boundary experiments or boundary transgressions of STS and design. I could begin with a story that takes place just before I started on this PhD, at the EPIC conference 2008 in Copenhagen. In the opening hallway there was an installation on a display of what was called *Physical Bar Charts* (Barry and Kimbell, 2005). At the bottom of the bars or tubes it was possible to take out button badges – as many as you like. But as you take one, the bar goes down because the bar is made up of the badges. Many of the conference attendants took one or more and wore them. The badges had different pieces of texts e.g. “I think, then I act” and “I act, then I think”.

By looking at the bars from a distance, the conference audience could visualise, and talk about, which of the statements most people had chosen. The effect was that this installation sparked quite a lot of attention and as it turned out the “piece” (referencing the art world) was part of an argument made by Lucy Kimbell who was the closing keynote speaker on the conference. In her keynote talk, Kimbell (2008) used STS/ANT to illuminate ways in which

ethnography would benefit by connecting with (contemporary) art and design. Her main argument was that by looking at what designers and artists do, ethnographers might be able to engage new ways of *performing* their theories and analyses. She applies Latour and Woolgar's (1986) foregrounding of objects and their role in co-constituting social relations to illuminate how designers make use of objects to do exactly this; "[artists and designers] arrange people and objects into sets of relations, into actor-networks" (Kimbell, 2008, p. 7). As with their installation at the conference, these practices "involves crafting arrangements of humans and objects into accounts of human experience"; the badges at the conference became actors by sparking conversation, and in turn they produced temporary networks that made the installation "disappear" or create uncertainty regarding its location. That is, the tubes and badges are very visible objects, but the success of the piece lies in the badges being taken away:

*"The record of the taking of the badges produces the *Physical Bar Charts*, a visual account that shows, inversely, which badges are most popular. Data are created at the same time as the results of the data are assembled. And yet an important part of the piece is not documented – the traces that the badges leave in conversations here, or when you get home, or when you find a badge that pricks your finger when you put your hand into your pocket a month or two from now."* (ibid., p. 3)

Besides making the point that the badges and the bar charts are material or non-human actors that partake in producing the piece as a performed arrangement, Kimbell also includes a second concern in her talk, which is central to the questioning in this thesis. It has to do with the way ethnographers create accounts. She makes the point that ethnography on the conference is, still, dominated by words; "*we still expect to *read* the work of ethnographers*" (ibid. p. 1). By turning to design where the visual and material are dominating ways of accounting, Kimbell suggests that ethnographers could draw on these ways of *performing accounts*. Instead of working on translating analysis into text, ethnographers could engage in ways that perform or make assemblages of actor-networks similar to those created by designers. One consequence of conflating the making of empirical data with the making of representations is that the empirical ("data") and its representation emerges together, at the same time, as socio-material arrangements.

The Physical Bar Charts is an example of, the visualisation of the data i.e. the representation of how many have taken which badges, is entangled with the participants and many more things at the conference; "*Data are created at the same time as the results of the data are assembled*" (ibid., p. 3). The production of the empirical and the production of the analysis become inseparable – they are performed socio-material assemblages. One could say that it is an example of a performative mode of doing ethnography as opposed to a more traditional representationalist mode where text is the means of making an account; "*Data*

are gathered, data are represented, and theories of the social are entangled with the experience of the form of the work” (ibid.).

I would like to make an insertion here, because in many ways Kimbell’s examples resemble what we were well into doing in our prototyping process of design-in-use. It is almost as if the participants’ use is, itself, analysis that is socio-materially *performed*. Whether we were present in design interventions or not, gathering data to write about it, the ethnographic concepts embodied in the prototype were somehow still performed. As with the Physical Bar Charts at the EPIC conference, analysis had, for us, taken new form. Instead of waiting for us, designer researchers, to observe or hold fast in various ways to later write about it, analysis was still happening – not as text but as real prototypes, patients and so on.

Yet, there was another talk at the EPIC’08 conference, which engaged STS and design. Joachim Halse and Brendon Clark (2008) presented their paper “Design rituals and performative ethnography”. Here they employ STS as a way of exploring how the paradigmatic shift, from a realist ontological mode towards a performative ontological mode, of doing ethnography and design could be. Halse and Clark call themselves “design oriented anthropologists” who report from experiments on projects that have been carried out in the Scandinavian Tradition of Participatory Design. That is, they work to create ethnography and participatory design. They discuss how to analytically understand ethnographically experienced practice in terms of performativity and thereby contribute to a “reflexive design anthropological practice”. They ask the question: “*Could we improve the efficacy of the design process by conceiving of it as a performance?*” (ibid., 131). To answer this question, they problematise the principled sense of performativity in STS: “*If everything is performative, then it is nothing special to state that particular collaborative design events work by performing that which they want to create [...] If everything is enacted, then facilitating a particular user’s enactment of a future scenario merely states the obvious.*” (ibid., p. 133).

This philosophical problem of being caught up in the constant, all-encompassing process of relational transformation – “*the continual process of becoming through our engagement with it*”, is in conflict with the proposed dynamics in participatory design: “*that it works by performing that which it wants to create*” (Binder, 2008). As a solution, they suggest to eclectically turn to the dramaturgical sense of performativity, as used by Erving Goffman. This enables engagement of the famous “what if” in design situations and thus provides the durability to extend alternative definitions of a collaborative design situation i.e. engage the transformative potential of the situation.

Whereas Kimbell goes to suggest that the practices of contemporary art and design could be a way forward for ethnography, Halse and Clark point to the principled paradox of engaging a performative ontology to the integration

of ethnography and design. They dig out the weaknesses that any all-encompassing theory or philosophy have, and which John Law himself acknowledges: “*A consequence is that everything is uncertain and reversible, *at least in principle**” (1999, p. 4 emphasis added). However, with this thesis I have not gone as far as Halse and Clark and it is therefore not my intention to continue this line of critical thought but moreover to open up and consider the possibilities of employing STS and ANT in the integration of design and ethnography.

Looking to other occasions that, similar to the EPIC’08 conference engages discussions of the intersecting traffic between STS and design, it is noteworthy that some of the pioneers of CSCW and the Scandinavian tradition of Participatory Design are active in this movement. During a mini-conference³⁵, “Entangling Design and Social Science” (Wilkie, Alex et al., 2010), which was held in September 2010 at Goldsmiths, University of London, the aim was to contribute towards the move beyond the traditional pattern in which design and social science have been conceived. In the call, the organisers pose questions of how the practices of designers might furnish social science with new insights into the study and articulation of society, and how social science’s interest in complexity might contribute to the iterative process of making in design – and at last; “*In what ways might these fit together or articulate?*”.

By these questions they move away from what have been a tendency so far; social scientists treating design as a topic (“*e.g. what does design do and how might this be accounted for in sociological terms?*”) and designers treating social science as a resource (“*e.g. what useful knowledge does sociology produce and how can this be deployed to model users or construct scenarios?*”)³⁶.

Another conference, the EASST’10 conference in Trento, Italy, confirms the emergent research interest that centres on entanglements of STS and design. This is where Jonas Moll and I presented our abstract of “Prototyping Patient 2.0”, which is part of the last case that I develop below. For now, I want to keep at what could be concluded from the conference proceedings. In a discussion with Peter Danholt, one of the organisers of the tracks in which

³⁵ I deliberately call it “mini” because when I found the call for registration, it was too late – the organizers had chosen to keep the maximum delegates to 60. Applying for exception, Nina Wakeford, one of the organizers, replied in email: “*Actually we are totally oversubscribed for both events with a waiting list! I thought it had been circulated around many email lists, so it is a pity it didn’t reach you sooner!*”. My point here is that the theme of the conference attracted more people than room could afford, indicating its timely questions and theme (and moreover that I was not part of the emergent discourse, *yet* [i.e. the mailing lists]).

³⁶ What this mini-conference confirm, is the collective effort of drawing disciplines together and that the emergent interest is pushed by researchers that have pioneered the fields from where this thesis depart – and end; Pelle Ehn, Lucy Suchman, Nina Wakeford, Mike Michael, Bill Moggridge, and Bill Gaver.

we participated, he said that what was interesting about the contributions they received (many more than expected) was that the papers could be grouped in two; one that employs traditional STS methods to account on the phenomenon of “patient 2.0” and then a group of papers that eclectically mix design and STS methodology in some way or another to account (while producing) patient 2.0. In taking note of this, Danholt speaks of three other tracks and a subplenary session that signify new grounds of interdisciplinary engagements of STS and design:

“Track 2. Design, Performativity, STS

Track 4. What Objects Do: Design, Consumption and Social Practices

Track 9. Speculation, Design, Public and Participatory Technoscience: Possibilities and Critical Perspectives

Subplenary session: “On (the) Doing (of) Things” by Liam Bannon and Pelle Ehn.”
(EASST’10, 2010)³⁷

For now, I have made my point clear that talks, conference papers, and discussions on the intersecting traffic between STS and design is well under way³⁸.

Then, where to look, next? Master courses, PhD courses, or summer schools? For a moment, I will keep looking to where new ideas of disciplinary experimentation have their open space. Again, this is not an exhaustive review but it is an attempt to get to grips with those who are exploring this form of interdisciplinarity and what they are saying so far. As I have mentioned above, the STS-design method endeavour has interests from both sides. It is not like in the days of Xerox Parc where (primarily) innovative ethnomethodologists had an interest in the possibilities of applying ethnography to systems design or as in the days where Latour and Woolgar did laboratory studies. What characterises the formation of the STS-design method discourse is that it is explored from two sides at the same time, almost to a degree that makes the “two sides” disappear. The Nordic Design Research Conference (NORDES) community arranges a biannual summer school for PhD students in design related areas and in 2010 the theme was “(The doing of) Design Things”. Here ‘the doing’ is a pronounced reference to a performative ontology of design and ‘design things’ of ANT and the posthuman inclusion of the non-human. The call suggests exploring design not only as “*objects*, products, artefacts and services” but moreover as “*assemblages*, processes, projects and even parliaments” – a clear reference to STS literature, which is also part of the reading list (Bruno Latour, Annemarie Mol, Susan Leigh Star and others).

³⁷ Interestingly, the EASST’12 will be held in Copenhagen with the theme indicating interest for design: “Design and displacement – social studies of science and technology”

³⁸ With paper 3, Halse, Moll and I participated in the NORDES’11 conference, bringing STS-design exploration to the Nordic Design Research Community (along with others, see e.g. (Lindström and Ståhl, 2011)).

However, the seminars were based on the book “Design Things” (Binder, T. et al., 2011) which engages with performative ontology. The book has been published recently.

Binder et al.’s (2011) book, brings me to the last major resource that signifies the becoming of a new interdisciplinary field or discourse³⁹. PhD theses, journal papers and books are perhaps the sources, which most firmly anchor the emergent discourse. However, As most of the theses and books have been published fairly recently, I will keep to mentioning those, which I have managed to become aware of and draw out some lines from the ones I have had a chance to incorporate in this thesis.

Nina Wakeford and Celia Lury (2012) are editors of an anthology, which is a collection of writings that build on methodologies, which cut across disciplines to investigate the contemporary world on its changing premises⁴⁰. Various “devices”⁴¹ are explored in terms of being “inventive”. Said otherwise, it is a (sociology) book on “inventive methods” thus emphasising the (need for) generative or performative methods. In the introductory chapter, they state, *“if methods are to be inventive they should not leave that problem untouched. In short, inventive methods are ways to introduce answerability into a problem. And, some might say, questionability into methods”* (ibid.). Methods that have the capacity of being inventive are “multifarious instruments” – they have a variety and variability of purpose. Wakeford and Lury summarise and propose inventiveness of methods to lie in the relation between the addressing of a method *“and the capacity of what emerges in the use of that method to change the problem. It is this combination, we suggest, that makes a method answerable to its problem”* (ibid.). Inventive methods are therefore something that only emerges through a reflexive relevant-making of the method and inventiveness then becomes a matter of use, of collaboration, of situatedness and cannot be given in advance.

³⁹ There are increasingly many seminars, workshops and mini-conferences that touch on the STS-design subject. This includes: A PhD course at Denmark’s Design School April-June 2011, entitled “DESIGN & THE SOCIAL” focusing on the convergence of STS and Design. Another PhD course “London D! Internat” held in May 2011 at Goldsmiths College was arranged to introduce Swedish Design Research PhD students to the currently strong collaboration between the Design and Sociology department at Goldsmiths, University of London. Speakers include Alex Wilkie and Bill Gaver from Design and Nina Wakeford and Mike Michael from Sociology. I participated in this.

The same is the case with PhD Programmes and courses. See for example Goldsmiths MPhil & PhD in Visual Sociology Programme which draw on sociology (incl. STS) and art and design practice and “experiments” with a new form of PhD thesis. As far as I remember min. 30% needs to be visual i.e. photo or video and 70% text.

⁴⁰ Wakeford and Lury refer to the changing conceptions of the empirical, the intensification of interest in interdisciplinary work, and the growing need to communicate with diverse users and audiences

⁴¹ Examples of “devices” include: Anecdote by Mike Michael, Configuration by Lucy Suchman, Experimentalism by Steven Brown, and Probes by Kirsten Boehner, William Gaver and Andy Boucher.

A further characteristic is that the use of inventive methods “*is always oriented towards making a difference*” [i.e. changing the world to something else] (ibid.).

As Wakeford and Lury make their argument from a sociologic point of view their characterisation of the inventiveness of methods is very much in line with Kimbell (2008), Halse and Clark (2008) and others who have engaged discussions on performative ethnography or design anthropology. What is shared is the concern for methods that take serious the inventiveness of the relation between the object of research and the way it is researched. For example, and this is also to point to a book that speaks of the same project of research as I am foregrounding here, Joachim Halse (2010, p. 148), who states:

“Design and ethnography are both concerned with subject matters that are not given [...] The effort here is not so much “we researchers understanding [x]” as it is about collectively rehearsing how [x] might become something else by the aid of technology.”

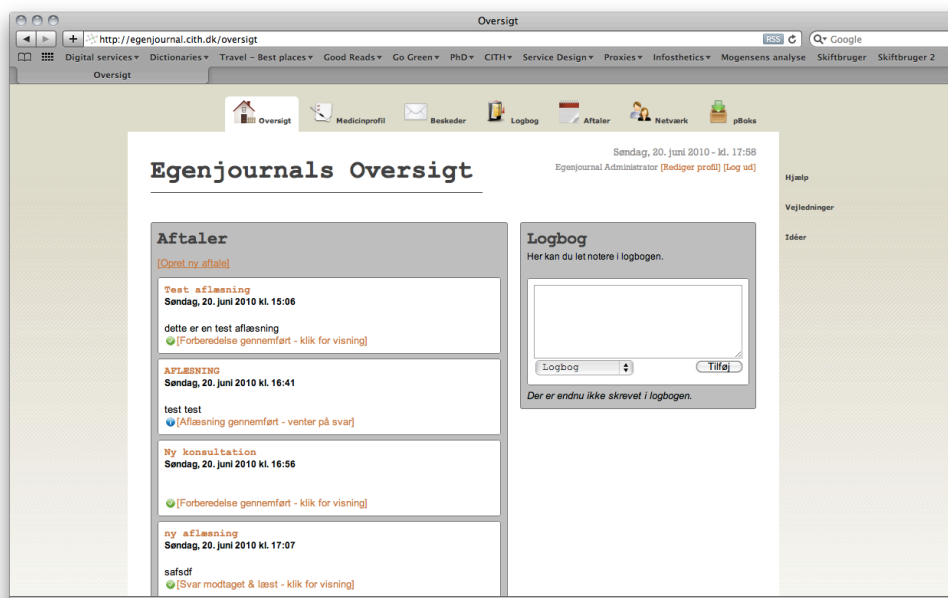
What Halse draws attention to here, is the generative capacity of the method assemblage of performative ethnography and participatory design – the capacity to change the problem while making it answerable and, importantly, questionable. In his thesis, Halse (2008) employs performative ontology and participatory design experiments to suggest a different way of doing ethnography. He suggests using exploratory design inquiries as an actual ethnographic strategy. In this way he installs a mode of inventiveness in the ethnographic approach. As a strategy for not being caught up in “problem space” or in a mode of ethnography where problems and answers go hand in hand, Halse suggests a new way for the ethnographer to deal with these issues; to look to participatory design experiments and a reflexivity that engages proactively “with the idea that things could be different” (ibid. p. 31). This involves “*asking the playful follow-up question that is usually not posed in traditional ethnography: what if things *were* different? What if airy ideas about better practices and wishful thinking about more interesting technological experiences were given some sort of tangible form? How would they play out among the subjects of the study, if they were invited to partake in the experiment?*” (ibid.).

In Peter Danholt’s (2008) dissertation, he engages posthuman performativity and design in related ways to that of Halse. But while Halse is enthusiastic about the possibilities for a design anthropologist to install a sense of questionability from design into the ethnographic approach, Danholt is critically reluctant and argues that it is the problem (of diabetes) that we need to engage inventively. Danholt approaches “the problem of diabetes” in designerly ways by introducing a diabetes technological solution to patients. By means of this re-configuration he explores diabetes as contemporary societal problem. However, the tool is a means of getting to the constitution of the problem of diabetes and not a way to engage the actual (re-)design of technological solutions. Said otherwise, Danholt keeps a clear line of

accountability to the study of diabetes (he is a researcher, not a designer) whereas Halse take serious his accountability as both an ethnographer and as a designer (examining the problem, but also seriously suggesting solutions). It is therefore Halse and others' commitment to the participatory design experiment that I submit to. This is the reason why I have, in this section of the thesis, presented some forms of STS-design entanglements that I see my work as related to. For other PhD theses that have similarly engaged STS and design and which have related, if not the same, research heritage as Halse, Danholt and my own, see e.g. (Clark, 2007; Johannsen, 2009; Pedersen, 2007; Storni, 2007; Wilkie, A., 2010)

www.myrecord.cith.dk [Prototype v. 3.0]

Now, before I continue to the last case, I need to list the features of prototype v. 3.0. As part of maturing the prototype we changed its name from Inform to *myRecord* (or Egenjournalen in Danish) and it was accessible on www.egenjournalen.cith.dk. In many ways it builds on v. 2.0 but there are new features, which I already have introduced. There is a lot to be told about the features, but as I made the case on the tensions of writing up the action research study, I will leave the features to be described as part of the following case. Anyhow, the list is as follows: Overview (appointments), Personal profile, Logbook, Medication profile, Network, Messages, Guidance and pBox.



Screenshot of front page of v. 3.1 of the prototype, myRecord

Prototyping a collective

The following section is the concluding section of the extended summary, and thus, the whole thesis. As a way to extend the main points and propositions put forth, I will include the last paper (Paper 5) to make the case of “Prototyping Patient 2.0”. In this way, Paper 5 resources the last part of my argument, which I will develop in the following. What may become apparent is that this contribution does not bring closure to the possibilities of relating design and ethnography in the same way as the thesis’ papers do in themselves. Instead of reproducing traditional methods, I take the opportunity of this thesis to do as Kimbell, Halse and others, to suggest how performative ethnography and participatory design of novel technologies for healthcare can benefit from a particular form of interventionist, experimental, explorative and/or inventive approach to the matter at hand.

I summarise this by packing the main propositions from the (un)productive tensions explored above, into an approach of *prototyping a collective*. This underscores, among other things, that designing and researching is more about exploring how new configurations of problems and technological solutions could *become* together than it is to create a better understanding of a particular problem *and/or* to create “better” designed technology. By prototyping a collective, problem and solution make each other and therefore emerge as being performed simultaneously and important, collectively. The empirical and the analytical are performed relationally and therefore they become inseparable. I will return to this in more detail, below.

Prototyping Patient 2.0 [Paper 5]

Paper 5, ‘Medication Management in the Making: On Ethnography-Design Relations’ is in many ways a condensed form of this synopsis, but it does not come all the way around the summarising argument that I wish to make. The paper rests on one of the problems that this thesis departs from. It concerns the problem of the much-debated essentially disciplinary relation between ethnography and design. In critical opposition to the keeping of a disciplinary divide the paper goes on to promote participatory design and ethnographic inquiry as interdependent and mutually constituting. By turning to a performative ontology and multiplicity it is argued that through design interventions with working prototypes, ethnographic inquiry is proactively enacted. The concept of “medication management” is used not only as a narrative device, but moreover to illustrate how a new form of collaborative management of medication has emerged through assemblages of ethnographic and participatory design enactments. In this way, the paper favours the principles of a performative ontology (objects continuously become what they are through their relational performance) and only in the last part, the paper goes on to propose how a proactive and interventionist move makes possibilities for medication management to become something else (see Halse

and Clark, 2008, p. 7). The paper does not respond to the principled paradox of performativity, which Halse and Clark points to. The paper stays, more or less, close to the analytical commitment of seeing medication management, and its new forms, as emergent and relational and does not emphasise the way in which we (design researchers) have been working very hard to critically push for medication management to be something else. This is what I will do now. I will show how we have, as Berg (1998) calls, “come full circle” and employed social science theory (and philosophy) in participatory design to transcend the way ethnography and participatory design traditionally is employed. I will take in to consideration how our method is inventive and interventionist and illustrate, how the production of the empirical and the production of the analytical become inseparable as performed socio-material assemblages (Kimbell, 2008).

To make the case of (prototyping) patient 2.0 I need to reverse in time a bit and revisit an internal design-research session in the summer of 2010. The second version of the prototype was out and we were trying to conceptualise v. 3.0 in terms of how the different features of the prototype (old and new) and analytical concepts from the literature (e.g. ethnographic studies) could relate and possibly perform the figure of patient 2.0. As I have already discussed to some extent, we were interested in ways to impose insights from the literature in the design of the prototype as ways to experiment with the performance of analytical concepts in design. This counts for our ethnographic curiosity and for our interest in methodological experimentation. This eclectic and to some extent absurd idea of performing or designing/programming insights into the prototype and thereby to transport and enact them in a new setting, turned out to be fruitful for getting at this thesis main argument summarised as; Prototyping a collective. However, there is also another interest that needs to be mentioned; an interest in responding to a call for paper.

At the time of the design research session in 2010 at the university, we had already established several concepts and papers with various analytical insights that we found useful when discussing empirical examples or when designing new features of the prototype. This includes ‘diagnostic agency’ (Oudshoorn, N, 2008), ‘homework’ (Grøn et al., 2008), and ‘invisible patient work’ (Unruh and Pratt, 2008), which I have also introduced in several of the thesis papers. We had also, fairly recently been made aware of the notion of “patient 2.0” through a call for the EASST’10 conference: *“TRACK 26. THE SHAPING OF PATIENT 2.0. – EXPLORING AGENCIES, TECHNOLOGIES AND DISCOURSES IN NEW HEALTHCARE PRACTICES”* (EASST’10, 2010). We found the concept of patient 2.0 particularly useful, especially because of its composition and its reference to both ANT and the internet-age; a paradigm where technology empowers people, democracy thrives, and collaboration across boundaries pushes for globalisation. However, the most powerful about the concept, as we saw it, is

that it insinuates something that exists only as emergent or intangible phenomena.

For example, 'homework' is somehow much more directly applicable; it allows us to talk about work as a special kind of work and we can easily give empirical examples of it. This is different with patient 2.0; it invites multiple instantiations and emphasises a relational understanding. For example, it is more difficult to apply it directly as a reference (similar to web 2.0); "she is a patient 2.0" does not really make sense but what makes more sense is to give examples that resonates with "she performs or becomes a kind of patient 2.0". Patient 2.0 is immediately relational. This intangibility of the concept is also linked with the fact that the concept has not taken any definite form in the literature. Bos et al. (2008) coin the notion of "patient 2.0 empowerment", not by empirical reference, but by building it up through references to already established concepts or research findings. For example, they use research formulated under "patient empowerment", "Web 2.0", "Health 2.0", "telecare", "patient networks", and "PHR (Personal Health Record)" to define patient 2.0. Several times they state that *"real definitions of patient empowerment are hard to find"* and *"it is hard to find a definition of what Web 2.0 really is"* and in response they engage in a conceptualisation that is abstract and mostly speculative, as in "how it could be" or "what the potentials are". Not that this is bad, quite the contrary, it is very constructive.

Equipped with a range of concepts and a 'real' network of patients and clinicians using the second version of the prototype, Jonas and I discussed in what ways we could mobilise patient 2.0 as part of our design research experiments. We found that we were in a position to research patient 2.0 as only very few were, namely because we could engage an already established network of healthcare participants and a prototype that was both a tool for the healthcare participants and us as design researchers. We could partake in the enactment of a certain kind of patient, empowered with a certain kind of technology. By design interventions we could, in collaboration with patients and clinicians, problematise patients as diagnostic agents who do homework but we could also, at the same time, engage them in proposing solutions and trying them out. That is, instead of approaching the emergent and contemporary figure of patient 2.0 in traditional ethnographic ways or, as Bos et al., in speculative ways, we could engage both. The prototype and its features and the possibility to continually shape it to address different interests or ideas, provided for an inventive method. Being in a design research session, sketching features of the next version, we were in a position of adjusting the prototype to become what Collins (1994) calls "research hardware". With the prototype we could use available technologies (http protocol, html, PHP, etc.) to make it possible to empirically produce patient 2.0.

What we did in that session, back in 2010, was to link features with literary concepts and to create a map of what could be called a method assemblage of participatory prototyping and performative ethnography. The map visualised the ways in which we could *perform* patient 2.0 (as a collage of features juxtaposed with selected concepts from ethnographies in healthcare) *to study it*. In pragmatic terms, we used the whiteboard to map out patient 2.0 in relation to the existing and new (co-designed) prototype features but also in relation to what concepts from the literature we saw as relevant to build up the inquiry. So for example, we would have “patient 2.0” in the centre of the whiteboard and an arrow towards the concept of “diagnostic agency” or “the self-reflecting and participating patient”. In-between those and on the arrow-line we wrote the name of the features of the prototype that could support a process of inquiry into that phenomena. In this example we thought that features such as Logbook, Messages, pBox, and Network could provide insights into diagnostic agency when in use by patients and clinicians (this is also discussed in paper 1). However, Network was a new feature that we discussed whether to try or not, but we had not sketched it or verified with Anselm, the prototype web developer, if time would allow him to develop such (a possibly complex) feature.

Either way, to continue the case I need to leave the design research session and recall a design intervention a couple of months later, I carried out in Lone’s home (a participating patient). Lone is a middle-aged woman (age 59), a bit overweight, who lives 30 km outside Copenhagen but near a larger town, Roskilde (one of Denmark’s oldest towns and famous in Europe for its yearly music festival; the Roskilde Festival). She lives together with her husband and their teenage son and daughter. They have a dog and live in a two stories house with a rose-garden and a shelter storing the husband’s sea kayaks. The house has a driveway with two cars. Lone is a very lively person and has a very positive attitude to life. She is curious, likes to talk and make conversation (this is my experience). She is a nursery teacher in a local kindergarten where the children seem to like her (I have visited her there). The way I got acquainted to her is a long story involving serendipity and many practicalities (see Paper 4), but what is different from some of the other participants is that I have followed her since a week after she had her ICD implantation.

Lone lives far from Copenhagen so I had borrowed my mother’s car to make the visit. I brought with me some rye bread for lunch, which we would have together in her house after talking about her experiences with the prototype and using it to prepare for an upcoming consultation. Just to recall; the second version of the prototype was accessible to the participating patients and the main purpose with the design intervention was to engage critical reflections and re-design of the prototype but also to co-design new features and discuss what could be interesting and relevant to Lone through using it.

We sat in the kitchen with coffee and her laptop at a round table and discussed her version of her medical history, which she had written in the Logbook (in her summerhouse and on my suggestion). Then we moved to talk about what settings she had selected in her Personal Profile. In v. 2.0 we experimented with two kinds of what could be called dummy features. This was an effective way for us to get early feedback on features we found potentially relevant from earlier co-design sessions and workshops. One dummy feature in the Personal Profile was four checkboxes where patients could select visibility settings of what others in the Network feature could see (e.g. name, picture, Logbook notes). Another related dummy feature was an image simulating the possibility to click a tab that says “Other people with ICD”. The image visualised checkboxes, tabs and text fields of features in the coming version. It was promoted by a label saying “coming in 3.0”.



Picture from design intervention in Lone's kitchen, May 2010

Pointing at the dummy tab Lone reads aloud and says: *“Other people with ICD. Well, we’re very different people. Some have hearing aid and some don’t have hearing aid, or what the heck. But I think what I can get out of this, is: I have some questions, maybe my husband have some questions, but maybe some other person asks questions that we have not thought of.... Then she continues: The reason I have not clicked the checkbox [dummy feature] for other users to see my writings is that I feel like - I think also that I said last time, I don’t want to sit and write with Aunt Oda from Southern Fyn [Danish proverb] and hear about her cat [laughing]. (Transcribed from audio and translated from Danish, design intervention, May 2010)*

Then I explain the purpose with the dummy feature: *“Well, the idea is that if you click this checkbox, then - in the next version, others will be able to see your medical history, but they will not see it is you or your name. But if you click that checkbox then they will be able to contact you by writing a message but, still, they do not see your name so you stay anonymous.”* Lone says: *Alright, that’s smart, and then I ask her: So if it was anonymous, would you then have something against others reading the medical history that you have written?* She says: *No, that should be all right.* Then I ask her, a bit enthusiastically: *But would you then, not, consider clicking the checkbox; [Others are welcome to see my medical history]?”* Lone says: *“Alllllright, I’ll do that” and clicks the checkbox.*



Picture of a magazine (Heart Association) with a story of Stig – an ICD patient, design intervention May 2010

This prompts her memory and she says she wants to show me something. She flicks through her paper binder and takes up a magazine from the Heart Association [See picture] and says: *“Now you just look here - it was actually a little funny because [points at a two-sided article with a family and a story about a patient with the same kind of ICD]. He is the 33 and it was actually his medical history that turned out to be really good to hear – how he feels a sense of security with the transmitter [telemedicine box linked wirelessly to the ICD] and some of the issues I experience such as; how to live with it and things like that. The way he describes it is actually really nice. He is also from this area, I can figure out. I agree with her that it is a funny coincidence. She continues: Yeesss, because it says that in 2007 he came home with his girlfriend from Roskilde Festival where he had worked as a volunteer. It is only people from this area who are allowed to work voluntarily. At home, then, he had a cardiac arrest.*

At this point, it would be fair to say that we were co-designing features of the prototype; it should be possible to be anonymous while sharing one's own medical history; only "patients-like-me" are interesting to communicate with etc. It would also be fair to say that this snippet, along with other conversations and time spend together with Lone, could be potentially interesting, ethnographically; to investigate how patients make use of other peoples' stories as a strategy to cope with the trauma and the new situation of living with an ICD. The becoming-a-patient is today linked with the possibility to read about other patients in for example a magazine or on the Internet. Patients are offered to go to information meetings (where I went along with Lone) and rehabilitation programs where they can meet with patients in similar situations, and so on. Methodologically both these strategies are familiar and design interventions, we have argued, are ways in which both interests (and many more) can be mobilised.

Now, there we were, sitting in the kitchen with coffee, Lone's laptop, the prototype and talking about possibilities with technology and what interesting things another patient says about remote ICD monitoring. What became clear to me, at that point, were two related things. First of all, if we developed the feature of Network (a dummy feature at that time), I could contact the patient from the magazine and ask if he would participate on the project and hope he would agree not to be anonymous and use Network. In other words, I could make it possible for Lone to easily contact a patient that says things that she finds interesting. We could design a feature and try it out. Secondly, by doing this (in the future) we could engage in what Vikkelsø (2007) calls "prospective analysis". Reminded by the mapping on the whiteboard, we could analyse the figure of patient 2.0 and the related ethnographic discourses, by making it possible to collaboratively perform it. We could make Lone *kin* (Haraway, 1997) with the patient in the magazine by means of prototyping. We could prototype patient 2.0 and thus integrate performative ethnography and participatory design-in-use – if Lone and the other patient agree and find it appealing.

So, I asked her: *"If he was sitting here, would you then ask him about something, now that you read this [pointing at the magazine]?"* "Yes, I think so", she says and then I continue: *"Maybe you have a few questions that you could write to him if he was accessible here in the prototype?"* "Yes, that might well be", she says and continues: *"What it makes me think is that he might have experience with something that might be helpful for me."*

We continue to talk about contacting other patients and whether or not we (design researchers) ought to be in contact with the Heart Association. After a while, it has reached lunchtime and Lone gets up, picks up the rye bread at the table, walks to the staircase and yells: *"Jonathan [her son] do you want to eat now?"*

After the design intervention in Lone's home Jonas, Finn and I decided to sketch and implement Network and Messages. I contacted the patient from the magazine who accepted to meet us and eventually was happy to participate in the project. Now, this was two lines of text describing what we did afterwards, but as I have already argued above, there were a whole lot of practicalities involved (see paper 4) and co-designing, sketching, and launching v. 3.0 of the prototype. However, this is what I want to extent here, but rather to end the case of prototyping patient 2.0.

As it turned out Stig, the patient from the Heart Association magazine set up his profile in myRecord (v. 3.0 of the prototype) to allow other patients on myRecord to see and contact him using Messages. Then in October 2010, six months after my meeting with Lone, I discover that she writes Stig a message: *"Hi Stig. My name is Lone and I heard through Tariq that you have a Facebook group [Stig is the organiser] for people with an ICD and therefore you might be able to help me. I've been denied an application for payment of lump sum for critical illness from my pension fund. They justify it by saying that my heart disease and getting an ICD is not on their list of what they pay for. Maybe you know someone who is in the same mess as me, or just someone who can help. I have contacted the Heart Association, and they can't help directly but they also wonder about the refusal. It's also surprising that it is only certain heart conditions, which are entitled. Hope you can help. Best regards Lone."* (Transcribed from Messages in myRecord and translated from Danish, October, 2010)

Stig responds the same day (we developed Messages to send an email when receiving a message in myRecord thereby integrating with participants' current infrastructure.): *"Hey. My pension fund also rejected me... since they don't recognize short QT [hereditary disorder] as critical... I died of it and was in a coma for 3 days! But if there are more people who will fight I'm ready"* (ibid.). After this Lone replies to Stig, saying that she does not have a Facebook account but that she wants to join the "fight" she just needs to contact a cardiologist and then find out how. In January 2011, the process of prototyping was suspended and I therefore do not have the story of how it developed from there. But what I do have is a good story of how we (Lone, the prototypes, the laptop, the Heart Association magazine, email, smart phones, a meeting room, Stig, the whiteboard, Anselm, Jonas, texts on patient 2.0, the EASST'10 call, the EPIC'08 conference in Copenhagen, and so on)⁴² worked to perform patient

⁴² To hint at the contribution of the thesis, I would like to recall the Callon (2004) quote from the first page of this summary. Also, Adele Clarke (2005) provides an inspiring analytic method for unboxing postmodern or posthumanist unfolding of situations. By the technique of "situational maps" she suggests concrete ways to work in a modernised mode of grounded theory. Clarke calls it 'situational analysis', which have been helpful for seeing how it is inherently a collective effort (human and non-human) to engage design interventions with working prototypes..

2.0. It becomes clear that patient 2.0 is a collective of human and non-human that together perform a particular version of patient 2.0.

Enacting and designing the empirical

The story, just told, complements paper 5 of the thesis by showing in what ways *we*, after hard work and long engagements, produced patient 2.0 to study it. It shows how we (design researchers) succeeded to enact a methodological experiment of combining methods that work primarily by asking questions such as; *what is patient 2.0?* and methods that work by performing questions such as; *what if it was something like this?*

In paper 5, I construct a narrative based on Mol's empirical philosophy of multiplicity and on the idea that medication management is something that emerges on the project through different practices. In this way medication management *becomes* in the meeting between practices of participatory design, ethnography, the patient, the cardiologist, and so on. The master narrative in the paper keeps to the principled idea of performativity wherein everything emerges as relational effects. However, this favours an ethnographic account of what happened and downplays the major participatory effort it actually was to make medication management something else. In many ways this works as a rhetorical trick because posthuman or performative ontology is not widely employed in CSCW – making the community less appreciative of 'radical' method experimentation, such as presented in the case of Lone.

So, in paper 5; instead of emphasising the case as "this is how we produced the phenomena we study", I spend most of the time making an account of how medication management emerged. Not that this is not how it happened. It is only one version of it but it is one version that somehow fits better with the methodological principles of methods, such as ethnomethodology, much more appreciated in CSCW. It fits better because it enacts an analysis that employs ethnography in more traditional (ethnomethodological) means; *this is what actually happened; this is how, in retrospect, medication management came to be studied and designed*. It is only in the last section of the paper, that I present the idea of how we end up producing what we also want to study and thus engaging a more performative and importantly, participatory design oriented version of ethnography.

The case of Lone shows that we were not the only ones enacting our interests (of methodological experimentation). As it turns out, Lone uses the prototype and the new feature, Network, in ways we did not imagine or think of. She participates in performing the 'what if' and not only the 'what is'. She becomes a participatory patient (paper 2) who engages in the project and makes use of it on her own terms. By using the prototype to write to Stig (the patient from the magazine) to ask for help in an insurance case, *Lone engages in*

*performing that which she wants to create*⁴³. This is somehow different than if we stick to the principles of a performative ontology, in the sense, that she does ‘more’ than participate in the performance of patient 2.0. So on the one hand, Lone makes it possible to empirically illustrate what patient 2.0 could be thought of as being. But on the other hand, she also engages in participatory design and does what she wants to do. So, instead of ‘just’ participating in performing or *enacting the empirical*⁴⁴ she participates in what we could, provokingly, call *designing the empirical*. In this way, I hold on to the general principles of design or participatory design, by believing that we humans – to some extent, are still capable of making better what we have. As Halse and Clark (2008) point to, it eclectically extends the principle terms of a performative ontology making intervention an active act that actually holds the potential to change or invent the world towards that which we want. By suggesting the combination of enacting and designing the empirical I emphasise that participatory design has an equal say when it comes to integrating ethnography and design. By the case of Lone, I submit to a position, as Halse and others (2010), who believe in the potential of participatory design as being capable of engaging that which we want to create.

What is prototyping a collective?

I would like to end the thesis by starting where I ended the case of Lone. In the last sentence I indicated that it was not Lone, alone, who performed patient 2.0. It was a collaborative effort. It was in part us, the design researchers and Stig, the patient from the magazine. Yet, it was many more; the magazine from the Heart Association for example. Prompted by the dummy features, Lone showed me the magazine and the story about Stig and from there I managed to convince him to participate in the project. So, the magazine is equally important. But then again, so was also the prototype v. 3.0 and the features Network and Messages. Without those, Lone could not have easily found Stig, and written him a message. But if it was also the prototype, then it must necessarily also have been Anselm who wrote the HTML, CSS and PHP code. Without a talented web developer we would have not been able to get the features implemented at that speed. That is, no working PhP code, no connection between Stig and Lone. However, the list could then go on forever and it would be everything related to making it possible for Lone to write to Stig, which would get on that list. And, to some extent, that is also the case. But as the ANT slogan teaches us, we should look for those actors that *do* something interesting; we should follow the actors themselves as Latour (2005) states and as we did with the early study of the referral (Part 1.0).

⁴³ The idea that “the dynamics of participatory design [is] that it works by performing that which it wants to create” I borrow from Halse and Clark (2008, p. 133) – who draws from Binder (2008).

⁴⁴ The idea of ‘enacting the empirical’ I have from my visit abroad, in a conversation with Alex Wilkie in the cafeteria at Goldsmiths, the University of London

If we chose to do this, to follow the actors that make a difference, then we will at some point run into the EASST'10 call for contributions on “The Shaping of Patient 2.0”. And we will find that the concept of patient 2.0 has been particularly generative and have done a lot of things in many places throughout the construction of the case of Lone, and Karl in paper 5. ‘Patient 2.0’ has, similar to ‘medication management’, emerged in different practices, in various situations and by means of a heterogeneous set of tools. However, it has also been generative and productive for making ethnographic accounts and participatory design. Patient 2.0 has in particular been effective in the making of method experiments with ethnography and participatory design. It has become a ‘device’ capable of invention (Lury and Wakeford, 2012).

So now, looking back, what we have done is that we have managed to collaboratively perform some versions of patient 2.0. We had devised a method that was incentive, not only in terms of introducing answerability into problems (e.g. what is patient 2.0?) but also by introducing questionability into the method (e.g. how might patient 2.0 be otherwise?). To use Kimbell’s terms, we had made a socio-technical arrangement, capable of performing analysis and design of patient 2.0.

On the project, we have made our instantiations of patient 2.0. To use a concept that matches the idea of making instances or trying something out and which permeates our participatory design method, then it must necessarily be ‘prototyping’. By using the concept of ‘prototyping’ as in performing assemblages of ethnography and design, it appears, that we have been *prototyping patient 2.0*. ‘Prototyping patient 2.0’ captures, in so many ways, what we have been doing and therefore it captures the essence of the outcome of our method experiments. Prototyping patient 2.0 describes our method of designing and enacting the empirical.

Having illustrated how I find ‘prototyping patient 2.0’ to be a good way of talking about what we have been doing and the method we have constructed, I would like to zoom out and bring back the ANT idea, that patient 2.0 is actually a network of things. Lone was not alone performing the particular version of patient 2.0 and the same is the situation with Karl in paper 5. As I have just argued, patient 2.0 is not a singular thing – it is a *collective*. This is in fact, the way I will end the argument of this thesis – yet, of course by starting to open it up. It is in part inspired by a question, which Mike Michael⁴⁵ asked me in a supervision meeting at Goldsmiths in the summer of 2011, talking about the idea of ‘prototyping patient 2.0’ and our methodological experimentation.

⁴⁵ Mike Michael is professor of Sociology of Science and Technology at Goldsmiths, the University of London

Mike asked me:

“What does it mean to prototype something, which is actually a collective?”

Or reformulated and shortened:

“What is prototyping a collective?”

This question abstracts – it sums it all up. It asks the question, which this thesis is an answer to. By imposing this question on the thesis as a whole, it appears that I have already answered it. By this I mean that ‘prototyping a collective’ in many ways captures the propositions I have raised from discussing the (un)productive tensions. As an outcome of the method experiments, ‘prototyping a collective’ exemplifies in what ways method assemblages of ethnography and participatory prototyping could be.

The term ‘prototyping’ is synonymous with a long tradition of participatory design – a tradition which this thesis is part of. As described in part 1.0, we have applied methods, tools, and techniques from participatory design. If we take all the co-design activities and the design interventions as a means to make prototypes, then ‘prototyping’ unites this *doing*. Without commitment and application of doing prototyping there would have been no prototypes in-use. Patients and clinicians would have not been able to create that which they want. And, without the commitment to participatory prototyping, there would have been no method experiments and philosophical reflections to write about. So, ‘prototyping’ is an approach that is particularly concerned with being object oriented and methodological at the same time. The making of objects, such as prototypes, and the object of reflexivity go hand in hand. This is how ‘prototyping’ embodies participatory design. But ‘prototyping’, also, connects very well with philosophies in STS (performative ontology and ANT). Philosophically, ‘prototyping’ is to acknowledge the world as being a continual process of becoming through our engagement with it. ‘Prototyping’ *is* an interventionist engagement with the world that embraces the potentialities of that which emerges. In our case, it is not only design and the reconfigured practices of use that are appointed to be emergent and potential. ‘Prototyping’ has moreover been a way of doing ethnography. Through our method assemblages, we have been enacting the objects we study. By prototyping we have enacted and designed the empirical. We could go so far to say that we have been prototyping the empirical.

The term ‘collective’ is, in the same ways as ‘prototyping’, a hybrid reference to where this thesis starts and ends. As I presented in part 1.0, participatory design is rooted in the Collective Resource Approach. It was an attempt to formulate a research approach for democratisation of systems design. This development mobilised several projects where researchers, union

members, and workers cooperated. Those early projects are, to a large extent, the roots of participatory design and the increased contemporary interest in user-centred innovation projects. 'Collective' thus insinuate a democratic orientation and the principle of involving all members in the design and research process. And this takes us to the next reference, which 'collective' embodies. Because, as theories and philosophies from STS has taught us, members include patients, cardiologists, and design researchers but also the non-humans.

Proposition 6: Prototyping a collective

I suggest Prototyping a collective to mean the creation of a method assemblage of participatory design and ethnography that works by performing socio-technical arrangements. It incites an experimental, explorative, interventionist and inventive approach and operates by a convergence of design and use. The object of design and research is not to make a prototype that is useful to its users or to make an account of what the problem is – it is both at the same time, because a useful prototype can only be useful if it is used and making an account of what is the problem can only be made by intervention and attempts at solving it.

Prototyping a collective is a suggestion of a way of ethnographically researching and participatory designing – *that which we want to create*. It is made possible by installing prospective analysis in the prototype to work in a mode that is *effecting ontological transformation in the objects and relations of research*. By boundary experiments or boundary transgressions of ethnography, participatory design and use, an *orientation towards re-conceiving both the object(s) of research and the relations between subjects and objects is achieved*.

As I opened the thesis with a cheerful and very inspiring quote from a text of Michel Callon, I would like to end with one, which is written as a conversation between Michel Callon and John Law (1995, p. 485):

“JOHN: Okay, Michel. Here's the big question. Are you an agent?

MICHEL: Oui. Effectivement. Pour l'instant j'agis comme quelqu'un qui est dote de ce que vous, les Anglophones, vous appelez "agency."

JOHN: So why is that? How come you're acting as if you've been endowed with agency right now? In what sense?

MICHEL: C'est parce-que pour l'instant-j'insiste sur ce point, pour l'instant je re-presente un collectif hybride. Et, simultanement, j'appartiens a un collectif hybride.

JOHN: Let me translate. You're saying that you're an actor here and, now because your voice re-presents a "hybrid collectivity." And because it is a part of it.

MICHEL: Non. Tu as tort. je ne re-presente pas une collectivite. Je re-presente un collectif. Les deux notions sont tres differentes.

JOHN: I'm losing confidence. I thought I could translate for you, but you're saying that I'm getting it wrong. You're saying that what you call a collectif is not a collectivity.

MICHEL: Oui, c'est cela.

JOHN: *Let me guess. A collectif is an emergent effect created by the interaction of the heterogeneous parts that make it up.*

MICHEL: *Oui, c'est a peu pres cela. Ce n'est pas du tout un ensemble de personnes deja-la et qui decident de se lier par une organisation commune.*

JOHN: *So it's the relations-and their heterogeneity-that are important. Relations which perform. Perform agency, at least in this case. Perform a collectivity to which your voice belongs. And for which, perhaps, some of the time, it speaks.*

MICHEL: *Nous y voila, mon cher colleague! Nous formons un collectif au nom duquel nous agissons. Tu me re-presentes autant que tu le re-presentes.*

JOHN: *Okay. I can speak for you, even belong to you, so long as I remember that a collectif is not a collectivity.*

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Appendix: Paper 1-5

- Paper 1 Andersen, T., Bjørn, P., Kensing, F., and Moll, J. (2010). Designing for collaborative interpretation in telemonitoring: Re-introducing patients as diagnostic agents, *International Journal of Medical Informatics*.
- Paper 2 Andersen, T. (2010). 'The Participatory Patient. In proc. of the *Participatory Design Conference (PDC'10)*, Sydney, Australia, 2010, p. 151-154.
- Paper 3 Andersen, T., Halse, J., and Moll, J. (2011). Design Interventions as Multiple Becomings of Healthcare. In proc. of the *Nordic Design Research Conference (NORDES'11)*, Helsinki, Finland, 2011, p. 11-20
- Paper 4 Andersen, T., Moll, J., and Monsted, T. (Submitted). Practicalities of Participatory Prototyping. *CoDesign, 2013* [Special issue: Codesigning through making]
- Paper 5 Andersen, T. (Submitted): Medication Management in the Making: On Ethnography-Design Relations. In proc. of the *Computer-Supported Cooperative Work Conference (CSCW'13)*, 2013.



Designing for collaborative interpretation in telemonitoring: Re-introducing patients as diagnostic agents

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ABSTRACT

Purpose: We investigate why clinicians experience problems interpreting implantable cardioverter-defibrillator (ICD) data when the patient is absent, and we explore how to re-introduce patients into the socio-technical setup of telemonitored interpretation practices. **Method:** An action research study with a design interventionist perspective was conducted to investigate the telemonitoring arrangement for chronic heart patients with ICDs and to identify the nature of the collaborative practices involved in ICD data interpretation. We diagnose the main challenges involved in collaborative interpretation practices. These insights were used to re-design the socio-technical setup of the telemonitoring practices by designing and building a web-based, patient-centric, collaborative application, myRecord, to re-introduce the patients as active participants into the telemonitoring setup. Finally, we introduce myRecord at Copenhagen University Hospital and evaluate the new practices and the collaborative technology related to the transformed role of the patients.

Results: The interpretation of ICD data is a collaborative practice engaging clinicians and patients and involving three separate collaborative processes: *interpretation of numbers*; *interpretation of general condition*; and *patient's interpretation of own condition and ICD data*. In a collocated setup, these three interpretation processes are entangled and seamlessly inter-related. However, in the current telemonitoring setup, only the interpretation of numbers process is fully supported, neglecting the two other processes, and, in particular, the role of the patient. By re-introducing patients into the socio-technical setup of telemonitoring through myRecord, our design acknowledges the collaborative nature of the interpretation process. However, re-introducing patients transforms their role, and leads to new transformed telemonitoring practices, different from both the current telemonitoring setup as well as from the collocated setup.

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Conclusion: Telemonitoring practices of patients with ICDs involve three entangled collaborative processes, whereas the existing socio-technical setup only mediate one. myRecord is designed as an add-on collaborative technology to mediate the two remaining collaborative processes. We argue that myRecord solves some of the problems with ICD data interpretation inherent in telemonitoring practices by providing a collaborative, asynchronous space for healthcare practitioners and patients to mediate the two processes that are otherwise lost. Our new socio-technical design also transforms the role of patients considerably, thus new studies should take these insights into consideration.

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1. Introduction

Health care is an inherently collaborative effort where multiple healthcare practitioners and patients collaborate in practices of diagnosing and treating health problems. Because of the collaborative nature of healthcare work, the technologies we design and bring to the setting should be thought of as collaborative technologies supporting collaborative work. Computer Supported Cooperative Work (CSCW) research is the “endeavor to understand the nature and requirements of cooperative work with the objective of designing computer-based technologies for cooperative work arrangements” [1, p. 11]. CSCW researchers have been investigating the collaborative practices within health care for two decades [2], yet the changing nature of health care, combined with new technological opportunities, continues to extend this research field and bring new challenges [3]. Implantable cardioverter-defibrillators (ICDs) are one of the new technologies changing healthcare practices for patients with heart problems. An ICD is an advanced pacemaker that can be implanted in patients at risk for sudden cardiac death due to ventricular fibrillation. It is designed to deliver electric shocks to restore the normal heart rhythm. The ICD also records data about detected arrhythmic events as well as selected overall conditions of the body. For example, some ICDs can provide information about rising fluid levels approximately 14 days before ordinary methods would detect the indications. The purpose of collecting these ICD data is to continuously monitor the chronic condition and to support decisions about whether or not particular interventions (e.g., change in medication or re-programming of the ICD) should be initiated.

Monitoring ICD data is basically a practice of collaborative interpretation where multiple healthcare practitioners and the patient together investigate the data, identify possible issues, and decide whether to take action. The monitoring activity traditionally took place collocated, where the patient traveled to the healthcare facility and advanced machinery read the ICD device, the output from which then formed the basis for data interpretation. However, in recent years ICD technology has started to include telemonitoring opportunities. Telemonitoring has transformed the practices of interpretation and use of ICD data, and some of the current ICD telemonitoring systems allow the patient to be located globally while being monitored locally.

We know that technology transforms practices in unanticipated ways [4]. However, because ICD telemonitoring technology is fairly new, its effects on the activity of data inter-

pretation have not yet been documented. While investigating the telemonitoring practices, we quickly realized that one consequence of telemonitoring was that the patient became absent from the interpretation practices, which was identified as problematic for the clinicians. Thus, in this paper we investigate why clinicians experience problems interpreting ICD data when the patient is absent, and we explore how patients could be re-introduced into the socio-technical setup of telemonitored interpretation practices.

Applying action research [5], we initially found that ICD data interpretation in the collocated setup was, in fact, a collaborative practice between the clinicians and the patient, that it comprised three seamlessly entangled processes, and that the current socio-technical telemonitoring setup only supported one of these processes, neglecting the role of the patient. Next, we designed an add-on patient-centric web-application, myRecord, with the aim of re-introducing the patient into the data interpretation process. The new socio-technical setup was then evaluated by both the healthcare practitioners and the patients. In this way we went through a full action research cycle of understanding, intervening, and evaluating [6], and, finally, we reflected on the transformed role of the patient.

The paper is structured as follows. First, we present previous work on patients as active participants in telemonitoring practices and interpretation. Then, we present the action research methodology including data sources and methods of analysis. Further, we show the results in three parts: understanding the interpretation work, intervening through design, and evaluating the intervention. This is followed by a discussion and, finally, we offer a conclusion.

1.1. Previous work: collaborative effort in telemonitoring

Collaboration occurs when multiple people are mutually dependent in their work, and it “is constituted by the interdependence of multiple actors who, in their individual activities, in changing the state of their individual field of work, also change the state of the field of work of others and who thus interact through changing the state of a common field of work” [7, p. 4]. The interaction between healthcare professionals and patients in the process of monitoring chronic illnesses is a long-term, collaborative effort. However, most research on telemonitoring tends to neglect the collaborative aspect and instead focuses on how treatment can be more cost efficient [8,9], or how monitoring might reduce the risk of mortality among heart failure patients [10–13]. Moreover, research on

how IT might improve the communication and information access within home telemonitoring is sparse [14]. While we do appreciate the mainstream research in telemonitoring, we believe a vital element of telemonitoring is being ignored: the collaborative effort.

Few researchers [15,16] appreciate the collaborative engagement in telemonitoring practices and few have investigated the inevitable transformation in the cooperative work caused by new technologies. Kaplan and Fitzgerald [16] investigate remote intensive telehealth care and provide interesting observations, but they explore the collaborative practices between dispersed healthcare practitioners and not the monitoring of patients. Bardram et al. [15] found that telemonitoring technologies transformed the practices by changing the division of work between the physician and the patient, placing new work tasks on the physician in terms of time and effort used to monitor, and that the communication patterns were transformed from a contextual, rich conversation to asynchronous messages [15]. New technologies transform medical practice, and studies have pointed to how the integration of new technologies leads to redistribution rather than reduction of work [e.g., 17].

Patients are an essential part of the collaborative engagement in the telemonitoring context, and it has been argued that patients are able to act as diagnostic agents in such setups [18]. Being a diagnostic agent, essential work is redistributed from the healthcare professionals to the patient, and often this new type of work disappears from the formal descriptions of telemedicine [18]. Oudshoorn introduces the concept of ‘diagnostic agent’ to capture the invisible work done by patients in telemonitoring. She argues that “[p]atients are not just users of a new technology that requires instrumental skills, but should be considered as agents that have to perform all manner of articulation work required to make these new healthcare services work.” [18, p. 276]. She builds the concept on empirical work of heart patients, who are equipped with a new technology – an ECG recorder. The responsibility of selecting the right moment to make an ECG is delegated to the patient. Becoming a diagnostic agent thereby depends on self-learning and trust in their own ability to make the right choices [ibid.]. When patients become “absent,” their condition is separated from the context of their bodies, and the “condition” becomes represented through particular forms of representation such as images and graphs [19]. This means that the healthcare practitioners must rely solely on representation to make sense of the context, which is a huge change from the practice in collocated settings.

Previous design-oriented research on telemonitoring practices suggests different web-based solutions for telemonitoring, where the patient and the healthcare practitioners, through one portal, can reach the clinical data collected in the patient’s home as well as the patient record [e.g., 20]. However, while these kinds of studies are mainly technically oriented, typically referring to laboratory installations, they do not take into account all of the organizational issues related to the real-life context that is included in our study. Even though previous design-oriented telemonitoring research tends to focus only on the technical aspects of the telemonitoring process, there is a trend in medical informatics [e.g., 21,22–24] toward more patient-centered approaches and the design

of computer supported cooperative systems [14, p. 570]. Our work is part of this trend.

1.2. Research setting: the CITH research project

The study presented here is part of the larger research project, Co-constructing IT and Healthcare (CITH). In this project, we explore communication and collaboration across institutional and professional boundaries in heterogeneous settings within healthcare. The CITH project analyzes existing collaborative practices among heterogeneous actors who manage patients with an ICD. The project aims at “designing, developing, and evaluating IT applications and services supporting the work of both healthcare professionals and patients” [25]. The authors are part of an interdisciplinary group with backgrounds in Cardiology, Health Informatics, Computer Science, and Sociology. We have also engaged ICD patients as active participants in defining the aim of the project as well as in its analyses, design, and evaluation activities.

1.2.1. The organizational context

The care for ICD patients involves multiple participants, including patients, relatives, general practitioners, lab technicians, bioanalysts, heart specialists, device specialists, nurses, clerks, social workers, etc. The main work takes place in three settings: the Heart Centre at Copenhagen University Hospital, patients’ homes, and local hospitals. The ICD patients from Denmark, Greenland, and the Faeroe Islands that are connected to the Heart Centre have the implantation and the device follow-ups conducted in Copenhagen even though some of these patients live far away. Patients not on the telemonitoring system travel quite far to get a device follow-up. It takes place every three months and consists of monitoring the ICD and taking action when it does not work correctly, or when it has to be re-programmed according to the patient’s changing condition. An increasing number of ICD patients have a telemonitoring setup at home that is able to read and send the status of the ICD to the Heart Centre. The local hospital’s responsibility is to stabilize the patient by checking and adjusting the medical treatment. This takes place during ambulatory visits every three months. However, the part of the CITH project presented here concentrates on the collaborative interpretation work performed by the healthcare professionals at the Heart Centre and by the patients.

2. Method

2.1. Action research

The relevance of expanding the medical informatics field toward a multi-disciplinary approach has been put forward convincingly [26]. Qualitative methodologies for the design and evaluation of technologies in healthcare are entering the field of healthcare informatics [22]. The methodology applied in this paper follows this tradition, emphasizing user-centric designs, and, in particular, we apply action research [6]. Action research comprises two iterative interrelated stages: diagnostics and therapeutics. The diagnostic stage involves a

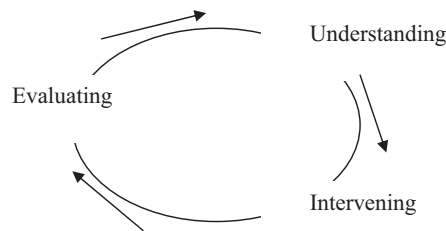


Fig. 1 – Action research cycle activities.

joint analysis between the practitioners and the researchers of an experienced problematic situation, while the therapeutic stage involves the introduction of changes combined with an analysis of the effects of these changes [5]. In our case, the starting point was the clinicians' statement that during ICD data interpretation practices they experienced that the absent patient was problematic; thus we initiated an in-depth qualitative investigation of the ICD interpretation practices. These investigations formed the diagnostic stage. Understanding why the absent patient was experienced as problematic, we then initiated the therapeutic stage of the research. Here we investigated, in joint collaboration with both the clinicians and patients, how it might be possible to re-introduce the patient into the socio-technical setup of telemonitored interpretation practices. This intervention took form as a combined design of both changed work practices and a new add-on technical application. Finally, we evaluated the intervention and the possible effects and consequences of such a transformed socio-technical setup. Action research seeks to contribute both to the practical concerns of a particular problem (the absent patient) and to the goals of scientific research (understanding the collaborative practices of ICD interpretation while designing collaborative technologies) by taking initiatives toward a joint venture between researchers and practitioners [27]. The joint effort was thus guided by the joint research question: Why do clinicians experience problems interpreting ICD data when the patient is absent, and how can patients be re-introduced into the socio-technical setup of telemonitored interpretation practices?

Action research within information systems and CSCW is well established, and even though there are multiple action research approaches, the fundamental activities and issues are similar [28–30]. In our work, the action cycle¹ is divided into three main activities: (1) understanding interpretation work, (2) intervening through design, and (3) evaluating the intervention (see Fig. 1).

Understanding interpretation work is the part of our study that focuses on diagnosing the problematic issues experienced by

the healthcare practitioners during ICD data interpretation in the telemonitoring setup. This process includes qualitative data collection, where we combine observations of work practices with interviews, identify the use of coordinative artefacts by various participants in particular situations, and reflect upon these findings together with our empirical partners.

Intervening through design is the second part of our study, where, based on the understanding achieved in the first part of the study, we initiate design activities together with the empirical partners. These activities include workshops with both patients and clinicians where together we develop mock-ups that are then turned into a web-based prototype. *Evaluating* is the third and final part of our study, where the designed prototype is placed within the actual practical situation of telemonitoring along with newly designed organizational practices. Evaluation includes activities such as educating the patients and clinicians about the transformed practices, as well as collecting data about the intervention and the consequences of the intervention. Because of the cyclic nature of action research, data analysis was continuously conducted in an iterative manner throughout the entire project. Results from, for example, observations and interview activities (understanding) were used in the initial prototype design (intervening), and then evaluated and discussed with patients and clinicians during workshops (evaluating). Thus, while the whole project enters one main action cycle guided by the research question, the main action cycle consisted of a large number of small action cycles, each entering the ring of understanding, intervening, and evaluating. Considering the criteria for action research, it is essential to understand that an action researcher cannot be a disinterested observer, but must act in practice to solve the experienced problematic situation while simultaneously observing oneself acting [32]. Thus, one of the key aspects of action research is intervention while collecting data about the intervention. Theory in action research is the analytical frame by which you investigate the domain. In our case the theoretical basis comprises the socio-technical approach, which stipulates that new technical systems cannot be understood as simply technical artefacts but should be understood in the context of use. We apply this theoretical approach when we examine the practices of interpretation as well as develop new designs supporting these practices. Theory in action research is also part of the results, so while we seek to solve the practical problem of collaborative ICD data interpretation, we also develop a theoretical framework of how to understand the practices of collaborative interpretation practices. In this way our theory about the domain is constructed during our investigations. Table 1 contains an overview of the data collection and activities forming the action research study. The setting of the intervention was designed as follows. Prior to the intervention, the socio-technical setup of telemonitoring at the Heart Centre consisted mainly of the telemonitoring system. Here, the bioanalyst can access various representations of patients' ICD data. With the intervention we implemented a new socio-technical system, myRecord. myRecord is an 'add-on' web-application installed on patients PCs that runs separately from the telemonitoring system. The intervention spanned two days where 23 patients took part in the study.

¹ Action research typically involves cycles of: problem identification, planning interventions, executing actions, observing the outcome, reflecting upon the results, while simultaneously collecting data about the situations and the interventions [31].

Table 1 – Data collection and activities forming the action research study.

| Type | Description | Proportion |
|--------------------------------|---|--|
| Included in the study | Involved in the co-construction of myRecord | 4 cardiologists 7 bioanalysts 2 secretaries 23 patients (myRecord users) |
| Observations of work practices | Heart Centre: collocated ICD interpretation Heart Centre: distributed ICD interpretation Patients' homes: daily practices Heart Centre: use of computer systems (lab systems, research applications, ICD register, patients records, ICD data) Local hospital: use of computer systems (lab systems, research applications, ICD register, patient records) Local hospital: patient follow-up | 8 patients (1 video documented) 9 × 4 h observations (126 telemonitored patients) 7 patients 5 × 4 h observations 2 × 4 h observations |
| Formal interviews | Clinician interviews | 12 patients (video documented) 8 w/cardiologists 2 w/bioanalysts 2 w/secretaries 1 group interview w/vendor |
| Informal interviews | Patient interviews During observations | 12 w/patient and relative 1 w/vendor consultant 5 w/bioanalysts 6 w/cardiologists 26 w/patients 3 w/secretaries |
| Workshops | Patient workshops Bioanalyst workshop Clinician workshops (Heart Centre and local hospital cardiologists) Demonstration of prototype for vendor Internal design workshops Heart Centre and local hospital | 4 × 3 h workshops (3 video documented) 1 × 2 h 5 bioanalysts 2 researchers (video documented) 4 × 2 h 2–4 cardiologists 3–5 researchers 2 h 2 IT vendor consultants 3 × 8 h workshops Collection of all types of documents: lists, plans, letters, forms, etc. |
| Document and artefact analysis | | |
| Prototyping | Sketching, prototyping and building new designs | 7 months – 4 iterations 1 part-time developer (387 h) |
| Intervention | Heart Centre: action research interventions | 2 days of 3 h 1 bioanalyst 1 cardiologist myRecord used by 23 patients in 4 weeks (video documented) |

3. Results

3.1. Understanding interpretation work

Interpretation work is the work done by participants when exploring and explaining the meaning of particular observa-

tions while presenting the results in understandable terms. Interpretation work of ICD data is thus the work where clinicians explore the numbers and graphs collected by the ICD device. These numbers and graphs are represented by the ICD monitoring system, and clinicians explain these data in understandable terms for both the patient and other health-care professionals. In this context, understandable terms refer

to what kind of action the patient and the clinicians should take based on the ICD data. Basically, the interpretation work can have six different outcomes: (1) re-programming the ICD device, (2) changes to the medication, (3) additional heart surgery (e.g., ablation), (4) replacement of the ICD device (e.g., battery replacement), (5) instructing patients (e.g., on how to act as an ICD patient), and (6) no actions needed. Thus, the main purpose of ICD data interpretation is to determine the appropriate action. Depending on which type of ICD a particular patient has, the data available for interpretation differs. However, all bursts, irregular heart rhythms, etc. are captured with date and time, enabling the creation of various time-accurate representations such as graphs and tables.

In the organizational setup we have investigated, the ICD data are available only at the Heart Centre. The interpretation work at the Heart Centre exists as two practices: collocated collaboration and distributed collaboration. In the collocated setting, the patient, the bioanalyst, and the cardiologist are all located at the Heart Centre, whereas in the distributed setting, the patient becomes geographically distant because of the telemonitoring setup.

3.1.1. Collocation: interpretation of ICD data

We are located at the Heart Centre, and an older lady is being examined. The bioanalyst asks the patient: "How are you feeling, and what kind of medication do you take?" The patient and the bioanalyst talk about the medication—the lady takes four different types of medication. Another bioanalyst reads the screen of the ICD telemonitoring system, while the patient holds the 'stick' (reader) near the heart. "What time is this? There are marks—February 9th, April 20th, and April 29th." The patient says that she had not felt anything. She cannot remember these dates. Then the patient remembers: "Oh...by the way, I did wake up screaming a few weeks ago, but I did not feel it." The bioanalyst says to the other bioanalyst: "How many ATPs²—one on three and then electric charge, VTs³ all of them—we need to call a cardiologist." The bioanalyst turns to the patient and explains: "You had 3 VFs⁴ with ATP and electric charge on all of them. They were all during night time, maybe that's why you did not notice. Maybe you had some bad dreams?" [...] After many examinations and discussions they summarize: "Well, we can say that the machine works as supposed to; however, the question remains: should we do anything?" To the patient they say: "Our cardiologist needs to check your medication." The cardiologist leaves to consult another cardiologist concerning the medication. Just before the patient leaves the Heart Centre, one of the bioanalysts tells the lady that if she experiences anything again (such as nightmares) she should call them up. (Observation notes, May 2009)

The above snapshot illustrates the crucial activities that are part of the collocated interpretation practice. First, it is

evident that although the Heart Centre's label for the interpretation practice is device follow-up and thus focuses on the device, the engagement with the patient is not solely concentrated on the ICD data (i.e., the numbers, tables, graphs, and percentages read by the ICD monitoring machine). The ICD data, as represented on the screen on the device, is interpreted by the two bioanalysts. However, this interpretation of the ICD data is highly supported by the bioanalyst's interpretation of the general condition of the patient, which, in many cases, is related to the medication list. The bioanalyst does not have electronic access to the medication lists, so this information is carried by the patient, who typically would bring out a piece of printed paper with the medication information. In all cases observed in the Heart Centre during device follow-up, the patient is asked: "How are you, and what medication do you take?" and the answer to these two questions provides the healthcare professionals essential and valuable information about how they should interpret the ICD data. It should be noted that the way patients answer these questions also affects the interpretation. For instance, if the patient is short of breath while answering, this is taken into account. During an informal interview with two bioanalysts, they explained that the patient's overall condition highly influenced their interpretation:

In cases where a patient expressed his or her overall condition as feeling good, then even "bad" data is taken less seriously, while in cases where the patients respond they feel bad, the healthcare professionals will take "good" data more seriously and go deeper into the interpretation. (Informal interview with two bioanalysts, October 2009)

Thus, in cases where the ICD reports OK, but the patient expresses feeling bad, lack of sleep, lack of breath, etc., the bioanalyst will not simply turn the patient away. Instead, they take the complaints of the patient seriously and take action.

Secondly, the snapshot also points to another essential activity providing crucial information important for the practice of interpreting ICD data, namely the patient's own interpretation of the ICD data. In the example, the healthcare professionals ask the patient about specific dates where the ICD had reported events. First, the patient cannot remember these dates, but then suddenly she remembers waking up screaming in the middle of the night. This explanation helps to make sense of the data, and the healthcare professionals interpret the experience of screaming as "bad dreams" related to the events marked in the ICD data, reading that the device had calculated risks of heart failure and then delivered a jolt of electricity to the heart a number of times.

So while device follow-up in collocated settings is about (1) interpreting the ICD data read by the ICD monitoring system and represented on the screen and printouts, the process of interpretation also includes information about the (2) patient's general condition as well as (3) the patient's interpretation of his or her own condition and ICD data. These interlinked processes of interpretation all together form the foundation for what actions would be appropriate in particular situations. Should they change the medication, should they re-program the device, or is the existing treatment accurate?

Summarizing, there are three main processes of interpretation going on during device follow-up in the collocated setting:

² Anti-Tachycardia Pacing (ATP) is a fast-pacing treatment for ventricular tachycardia (VT).

³ Ventricular tachycardia (VT) means fast heart rhythm and is potentially life-threatening because it may lead to sudden death.

⁴ Ventricular fibrillation (VF) is an uncoordinated contraction of the cardiac muscle of the ventricles in the heart. It is a medical emergency requiring immediate interventions due to high risk of sudden cardiac death.

the interpretation of numbers provided by ICD device data (as in graphs, diagrams, and percentages); the conversation with the patient about the general condition; and the patient's own experiences and thus interpretation of his or her own condition and ICD data.

3.1.2. Distribution: interpretation of ICD data

The system has detected two patients “with events”; however, the bioanalyst quickly browses through the information provided on these, but there is nothing of note. The browsing consists of opening the information on the screen, examining the values of certain data while examining the curves and graphs—is it stable or not? (Observation, May 2009)

The bioanalyst prints out the schedule for the day and sits by the computer screen logging onto the telemonitoring system. The telemonitoring system has pre-sorted the patients according to the system's algorithm. Thus, all of the patients that the algorithm has sorted as possible candidates for further examinations will be labelled as patients with “events.” However, all of the patients with an event are quickly dismissed as “no action needed” by the bioanalyst, and, interestingly, it is among the remaining patients that the bioanalyst identifies the patients that need further examinations.

The interesting observation here is the issue of sorting the patients. The telemonitoring system has done a pre-assessment of the data automatically and has placed the patients with registered events at the top of the list of patients. Here it is essential that the bioanalyst, after quickly browsing the ICD data from these particular patients, determines that the ICD data on these patients does not lead to particular concerns. Instead, the observation shows that investigating the ICD data sent by the telemonitoring system when sorting and selecting requires professional evaluation by a healthcare professional.

More patients have sent their ICD data, and the bioanalyst has sorted the patients, finding two that she decides to discuss with a cardiologist. The cardiologist sits next to the bioanalyst and they investigate the computer screen in front of them. “Look here [pointing to the screen]—it falls. It looks irregular and there are long periods. Then it becomes faster... 320... then back.” They discuss back and forth while trying to interpret the data. They are interrupted during their interpretation. First the bioanalyst is called away to the examination room, and then the cardiologist is called away to the operating room. The computer is left alone. The cardiologist returns. She browses through all of the data. The bioanalyst returns. “Here is one episode, are there more? It breaks... then the next episode, where it ramps... then it bursts.” The bioanalyst is supporting the cardiologist in reading the numbers and measurement. They talk about changing the medications. The patient had three incidents since March—they could ask the local hospital. [...] The cardiologist decides to telephone the patient, asking him to contact the local hospital.” (Observation, May, 2009)

The snapshot above illustrates the processes involved in interpreting ICD data when the patient and the healthcare professionals are geographically distributed and telemonitoring technology is applied. We see that the interpretation of the patient's condition based on the ICD data requires profoundly

varying amounts of work from the healthcare professionals. In some situations the condition of the patient is routinely and reliably determined based solely on the incoming data from the ICD. The healthcare professionals need no additional information to take proper action, and therefore no contextual information describing the patient in further detail is called upon. However, in other cases, the bioanalyst selects particular patients, who she decides to discuss with the cardiologist.

In the cases where the ICD data indicate problematic situations influencing the life of the patient, the geographical distance between the healthcare professionals and the patient complicate the interpretation practice. In the snapshot, we see how the bioanalyst and the cardiologist together interpret the ICD data through discussions and arguments. During the selected episode, the two healthcare professionals debate whether to change the medication of the patient; however, they lack access to the existing medication of the patient. The updated information about medication is in the local hospitals treating the patient. Exchange of medication information is clearly an issue for the people involved in the monitoring and treatment of patients with ICDs. In most cases, the exchange of information is done with the patient as a medium, transporting a folded piece of paper with the current medication record between healthcare professionals. In the case of telemonitoring, it is clearly problematic that the healthcare professionals do not have access to medication information, and in the episode reported here, they decide to telephone the local hospital for the information. However, further in the episode, it also becomes clear that they do not have access to change the medication. Changing medication is, in collocated settings, done by the cardiologist writing a prescription for the changed medication and handing this piece of paper to the patient. This is not possible in the telemonitoring situations. Given this complexity, the episode ends with the cardiologist deciding to telephone the patient and asking the patient to contact the local hospital. Here it is clear that the responsibility for taking initiative based on the interpretation of the data is distributed to the patient. In addition, this results in the patient receiving the complex task of explaining to the local hospital why he or she is contacting the local hospital. What was the issue with the ICD data, since the patient is contacting the hospital?

We see here how the entangled interpretation processes become detached from each other in the telemonitoring situation. In the collocated setting there were naturally attached connections between the numbers, the general condition, and the patient's interpretation; the distributed setting is distinctly different in the way that the collaborative effort from the patient is missing, thus the two interpretation processes concerning the general condition and the patient interpretation disappear, increasing the complexity in interpreting the ICD data for the healthcare professionals.

3.1.3. Implications for design: interpretation involves three entangled processes

In our empirical study, we found three main processes involved in the practice of interpreting ICD data. First, interpreting ICD data involves processes where healthcare professionals direct their attention toward the actual numbers, figures, tables, graphs, percentages, and diagrams

represented on a computer screen or printed out on paper. We will label this process *interpretation of numbers*. Second, we found that interpreting ICD data involves processes where healthcare professionals direct their attention toward the patient's general condition by asking the patient questions such as "how are you?" and "what kind of medication do you take?" In this practice, the patient collaborates by presenting the paper version of the medication list in the collocated situation. We will label this process *interpretation of general condition*. Finally, we found that interpreting ICD data involves processes where the healthcare professionals direct their attention toward the patient's own interpretation of both the condition and the interpretation of the ICD data. This process we label *patient's own interpretation of condition and ICD data*.

In the *collocated setting*, these three processes are entangled into one coherent practice of interpretation conducted as a collaborative activity between multiple healthcare professionals and the patient. Moreover, in many of the empirical observations, the patient family—or others accompanying the patient to the Heart Centre—were also included in the practice of interpreting data. Thus, interpreting ICD data is clearly a collaborative activity requiring highly specialized expertise in reading and interpreting the data as well as access to additional information about the patient.

In the *distributed setting*, the three processes of interpretation were not entangled and did not inform each other. Instead, it was clear that the existing telemonitoring system only supported one of the three processes, namely the *interpretation of numbers*. While the interpretation of numbers was adequate in all the cases where no action was required, it proved problematic in more complex cases. To solve these incidents, much detective work was required by the healthcare professionals. It also emerged from our empirical observations that not only did the lack of access to *interpret the general condition* and to the *patient's own interpretation* increase the complexity of the interpretation practices, it also shifted the responsibility for acting on the problematic condition detected by the healthcare professionals' interpretation of the ICD data.

The effort required for interpretation and investigation in the *telemonitoring setting* varies between cases, but in general two types of patient groups were detected. The largest group of patients, Group A, comprises cases where the bioanalyst decides that the ICD data are *sufficient* as information to determine the appropriate action. The smaller group, Group B, are patients where the bioanalyst decides that the ICD data are *deficient* as information to determine the appropriate action, thus additional information is required.

For the Group A patients, each "visit" takes less time than if the patient was physically present. The more complicated cases, however, take much detective work to solve. Thus, patients in Group B are the group of patients that take by far the most resources in the telemonitoring setting.

Based on the above study of the work practices involved in the interpretation of ICD data, we found that our design should re-introduce the patient into the collaborative interpretation practice in the distributed setting in order to re-convene the two interpretation processes that disappeared with the telemonitoring setup: *patient's general condition* and *patient's interpretation of own condition and ICD data*. Moreover, the design should support the interpretation work, especially in the

cases of patients in Group B, which are the most resource-demanding cases of interpretation.

3.2. Intervening through design

Informed by the implications for design, myRecord⁵ was designed and built as an add-on, patient-centric web-application with the intention to actively re-engage the patient in the process of interpretation, and, in particular, the processes of *patient's general condition* and *patient's interpretation of own condition and ICD data*.

With myRecord, we enable patients to flag attention, write in free text, and select medical categories to communicate their experienced symptoms. Patients can also create and approve their own detailed list of medicine, which then becomes available to the remote healthcare professionals. The bioanalysts and cardiologists can dictate messages and provide additional ICD data as a reply to the patients' comments and ICD transmission. In this way it supports asynchronous dialogue where patients' interpretation gets re-introduced through text and medical categories, while the healthcare professionals can respond by audio and text. With the design, we attempt to transform the current telemonitoring setup into a shared practice of interpretation, which employs the patient's own individual interpretation. By implementing myRecord into the distributed practice of interpretation, we intervene to explore and experiment with a re-organized telemonitoring practice. In the following we present the modules of myRecord that are designed to support collaborative interpretation work.

3.2.1. myRecord's modules

There are two modules of myRecord that support the interpretation of general condition and patient's interpretation of own condition and ICD data (see Fig. 2):

- Medicine List – a patient-generated, detailed, web-based list of medicine, which is editable and approvable by the patient.
- ICD Readings – a list of all scheduled ICD readings. Each reading includes a component where the patient can enter three levels of contextual information: (1) flag attention, (2) raise questions and describe experiences in free text, and (3) communicate symptoms using medical categories. Additionally, each patient can access the healthcare professionals' reply as audio, text, as well as a limited amount of ICD data values.

3.2.2. The Medicine List

With the Medicine List, patients can create a digital version of their medicine list, which most patients already have in memory or carry around on a piece of paper. It is designed

⁵ myRecord is a prototype of a patient-centric web-application that includes multiple features. To mention some, there is a module entitled 'LogBook,' which is designed for patients to keep an online diary, record symptoms, and write and organize their anamnesis. Another module, 'Profile,' enables patients to manage contacts, preferences, and personal information. A third module, 'Consultations,' is designed for patients to prepare for consultations, thereby qualifying both cardiologist and patients for a better dialogue.

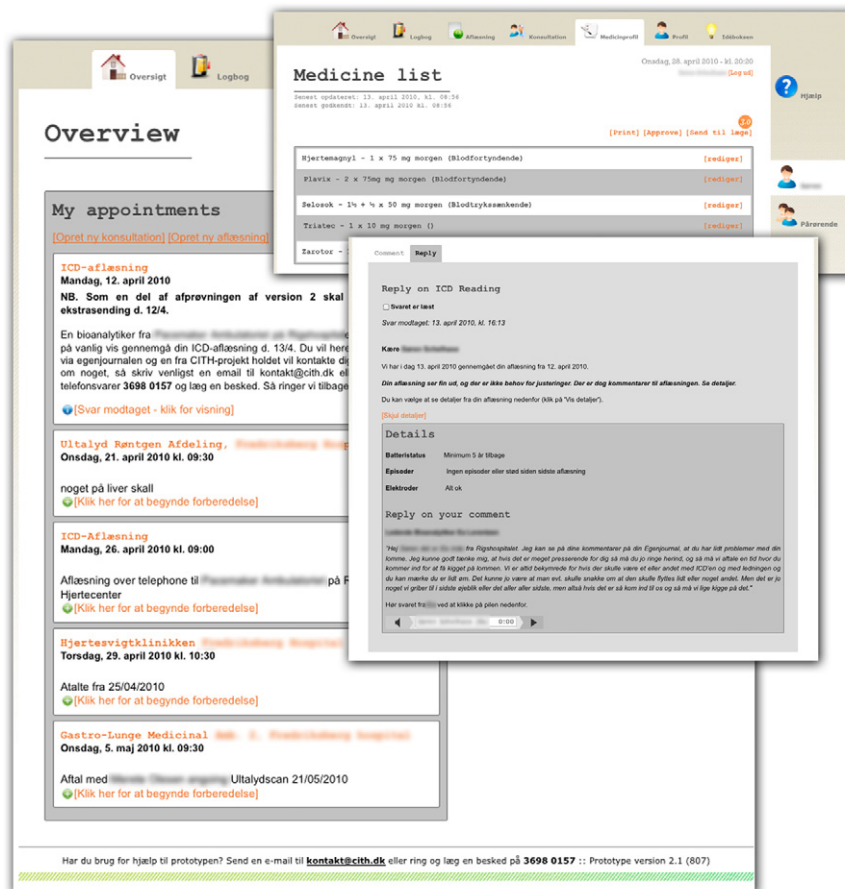


Fig. 2 – Illustration of myRecord's modules. Overview (Homepage), Medicine List and ICD Readings are shown.

to function as an up-to-date, online, shareable version of the patient's medicine list, thereby providing healthcare professionals as well as patients themselves with an overview of what medication they currently take. It is a simple, web-based list, which the patient can manually update by typing in information on each drug: name, strength, reason for prescription, amount, etc. For each drug, the patient can also record experienced side effects and deviations. The whole list is printable and has an "Approve" button, which timestamps the list to indicate when the patient has reviewed and approved the list. For reasons of supporting a shared practice of interpretation, distant patients can use the list to communicate important information concerning their status of medication to the healthcare professionals, which, in the collocated setting, was done through the patient's own paper-based list of medication.

3.2.3. ICD Readings – three levels of contextual information

ICD Readings is designed specifically to support a collaborative interpretation process for both patients and healthcare professionals. It holds a list of all previous and future scheduled ICD readings where each reading links to a page that has two components. One component, "Comment Your Reading," is designed to let the patient enter contextual information on three levels after having made the transmission, whereas

the other component, "See Reply," is designed to let patients access the healthcare professionals' reply as audio, text, as well as a few selected ICD data values. The "Comment Your Reading" component consists of three nested levels of contextual information. Initially, the patient is asked: "Has your situation worsened or are there significant changes since the last reading?" The patient then chooses either to communicate that everything is OK by clicking the button "Save and Send" or that the situation has changed, wherein expanded possibilities for explanation are revealed. We label this the "first level of contextual information" since the patient has the option to "Flag Attention" and thereby, with little effort, express that he or she is aware of something in relation to the ICD reading that needs the attention of a healthcare professional. At the second level of contextual information, the patient can describe their experience in free text. This option provides patients with the opportunity to use individual wording, expressions, and ways of formulating their interpretation of own condition and ICD data. The last step is the third level of contextual information. It consists of three text fields where the patient can enter their morning weight, blood pressure, and heart rate. It also includes nine sets of checkboxes where the patient can select medical symptom categories such as "chest pains," "shortness of breath," or "fainting" and whether it appears during heavy or light physical exercise, no physical exercise, etc.

The final component presents the healthcare professionals' reply to the reading, i.e., the result of the healthcare professionals' interpretation. The component is two-fold, showing both a standard reply on the reading (i.e., everything is fine, please contact us, etc.) and selected values from the ICD reading. The selected values are "battery level," "detailed information on episodes" (if any), including date, time, and type (pacing or shock), and a statement on the "status of the electrodes." The statement on battery level falls into three categories: at least five years left, at least two years left, and at least three months left. The last category indicates that a replacement of the battery should be scheduled within the following couple of months (the battery is replaced by renewing the whole ICD). Moreover, the healthcare professionals can, as mentioned, dictate a personal audio reply that is automatically transcribed and presented textually within this component.

3.3. Evaluating the intervention

The intervention was carried out over a period of four weeks and included 23 ICD patients. All patients were scheduled for an extra ICD transmission with the telemonitoring setup, and 21 managed to use myRecord to engage in the new collaborative practice of interpretation. One patient was unable to carry out the task because of a re-scheduled vacation and another excluded himself from the study by neither making a transmission nor using myRecord. Out of the 21 patients, 18 were initially classified as Group A and the remaining 3 as Group B. Out of the 18 patients, 10 confirmed the classification as Group A. However, 8 of the initially classified Group A patients ended up as classified Group B patients. We tested myRecord at the Heart Centre by observing transformations of the current distributed interpretation practice by requiring the healthcare professionals to take the patients' recordings into account *after* their initial interpretation of the ICD data. In this way we were able to observe how the patients' recordings changed the current telemonitoring practice. The observations of the healthcare professionals' use of myRecord took place over two days at the Heart Centre.

3.3.1. Hidden Group B patients revealed

Nearly half of all patients from the experiment (10 of 21) were classified by the bioanalyst as Group A patients ("nothing to note" or "everything looks fine" and therefore resulting in a "no action is needed" reply). In these cases, the bioanalyst based her interpretation solely on the transmitted ICD data, thus only on the *interpretation of numbers process*. Every patient in this group also used myRecord to signal whether or not their situation had changed. They therefore completed the use of myRecord with no messages and no pre-answered questions for the healthcare professionals. During the experiment, this relatively small piece of patient-produced information (flagging no attention) proved to work as an additional confirming statement that reassured the bioanalyst of her original conclusion. Thus, the patients' statement on their own condition (no news to report) together with the bioanalyst's original interpretation based on the numbers formed a simple collaborative interpretation practice. The bioanalyst could, with added confidence, continue her work based on a more informed and qualified decision.

In the cases where the patient "flagged attention," it also impacted the work of the bioanalyst. In cases where the bioanalyst initially concludes "no action needed" based on the device data alone, she immediately decides differently when confronted with the patient's written remarks in myRecord. One example is a patient who writes: *"I sometimes feel tender in the area where the ICD sits. It might just be me whining, but it feels as if it's the electrode [the lead connecting the ICD to the ventricle of the heart] that's attached to the vein. It pinches me"* (man, age 56). The patient's remarks and the indication that it might have to do with the lead causes the bioanalyst to respond by dictating a message to him, where she explains, *"from your comment I can see you are having some problems with your pocket [the implanted ICD is hidden in a little pocket-like breach in the chest]. We are always concerned about the condition of the ICD and the leads, and you feel a little sore. We might talk about moving it a little"* (bioanalyst's dictation, April 2010). This scenario illustrates how information from the patient describing an aspect of his own condition triggers and helps the healthcare professional to provide the patient with a calming answer, and it also provides an opportunity to teach the patient how to manage and react to important symptoms. Moreover, we see that the use of myRecord spurs a collaborative effort between the patients and the healthcare professionals.

In another case the bioanalyst initially classifies a woman (age 62) into Group A, but changes her mind based on the patient's information from myRecord. The patient documented in myRecord that she had experienced a "fluid alarm" on two specific dates. The bioanalyst quickly locates the date within the numbers and graphs and reiterates the values in her system to conclude the patient is right. As a reply to the woman's experience, the bioanalyst makes an elaborate dictation, explaining how the patient should stay alert the coming week by tracking her weight and contact her GP if the situation changes.

The three examples illustrate how the patient's own interpretation of condition and ICD data, mediated by myRecord, can have important consequences for the practice of interpretation. The patients' decision-making and ability to formulate their experiences provide the basis for establishing a remote collaborative process of interpretation.

3.3.2. Sufficient contextual information

In the evaluation of myRecord, we found that several patients made use of the healthcare professionals' pre-made symptom categories as a means of communicating their experienced symptoms. When patients use the symptom categories they collaborate by making sufficient contextual information available for the bioanalyst and the cardiologist so they can make an informed decision.

In one case the bioanalyst classifies a patient into Group A based on device data. The patient writes: *"under physical training at RH Monday [date] in the period around 3.15pm–3.45pm – several near-syncope and palpitation"* (man, age 61). Here the patient describes loss of consciousness and abnormal heartbeats. The patient also asks questions about the ICD data at particular times. This information makes the bioanalyst re-examine the device data, conclude that nothing is recorded, and explain that the patient's experience is not visible in the transmitted data. She then revisits his recordings in myRecord

and finds the patient's selection of two medical categories (level 3): "Heartbeats – Yes, under high physical activity" and "Near faint – Yes, under high physical activity" (man, age 61).

This information changes the bioanalyst's previous decision. She navigates to the values in the patient's device data, which describe what zones the patient's ICD is programmed to monitor. She uses the patient's textual description and selected categories to conclude that the monitor zone is not set up to record the patient's experienced event. She calls a physician for support and collects the device paper record. When the physician arrives, they use both levels of the patient's contextual information and compare it with the device data and information from the device paper record. They conclude and dictate two messages where they explain that his device is not programmed to monitor what he experiences, and they recommend that he make an appointment at the Heart Centre in order to adjust the monitor zone. As such, the patient's work of questioning and informing the bioanalyst and the cardiologist rightly impact the result of the interpretation process. The patient succeeded in providing sufficient contextual information to support the healthcare professionals' work of re-interpreting the device data.

3.3.3. ICD data made understandable

In the case of a woman (age 56) classified by the bioanalyst into Group A, the bioanalyst selects the device data to be presented in myRecord and notes that a replacement of the battery might soon be required. She communicates this by selecting the label "minimum 3 months left" in myRecord. The bioanalyst decides to use myRecord to dictate a message where she explains in more detail the reason behind the label and how the patient is to manage the situation "when the device starts beeping." The bioanalyst dictates, "We can tell from your ICD that you'll soon start beeping. It may be within the next six months to a year or even 1.5 years. But because the value of the battery decreases in stages, we cannot say exactly when it will be. You should just be aware that when it 'beeps,' you should call us. Then there are three months left on the battery before we need it changed" (bioanalyst's dictation, April 2010). The situation is interesting for two reasons. Prior to the introduction of the new telemonitoring practice, patients were (in the collocated setup) informed about the level of battery left on their device, and, in the case of "3 months left," they were given guidance and explanation similar to the above example. However, in the new practice, the Heart Centre do not to inform patients on their battery level because, as the bioanalyst explains, "it's simply not doable for us if we were to phone every patient upon every ICD scan, just to inform them on their level of battery. They already know that they should call us if their device starts beeping" (Informal interview with bioanalyst, April 2010). The bioanalyst knows from previous experience that labelling batteries "at least three months left" often causes anxiety and confusion for some patients. But the distributed nature of the telemonitoring practice has forced them to skip informing patients about batteries to avoid overhead work. The case illustrates how the new design holds the opportunity to re-introduce important but otherwise disregarded elements of the interpretation process. Specifically we see how the dictation feature in myRecord serves additional purposes, for example, as a feasible and convenient way to communicate important messages while still preserving the

benefits of asynchronous verbal communication. Patients are thereby helped in interpreting their own condition by ICD data being made (more) understandable.

3.3.4. Support for patient's own interpretation

During the evaluation we found that some patients used myRecord to support their own work of interpretation and self-diagnosis. Instead of simply commenting on experiences to aid the bioanalyst's reading of device data, some patients used myRecord to ask the bioanalyst to provide device data to them.

In one case a man (age 60) flags attention and asks how much his ICD has paced since last transmission. The bioanalyst responds by dictating an answer where she includes the value and that it is her interpretation that the ICD probably paces at night. Another patient writes: "Have NOT heard ALARM the last two mornings (after continuous alarm in 51 days) – is it correct? (Or have I become more deaf and/or battery flat?)" (man, age 62). The bioanalyst revisits the ICD data and responds by dictating a message where she confirms that the alarm has been off the past two days and calms him by telling him not to worry.

In another situation the bioanalyst found an episode in the ICD data. The patient (man, age 65) also flagged attention and described his experience and the date of the episode (using both the free text and the medical symptom categories). However, the event in the ICD data is different, and the bioanalyst decides to record a message where she recommends that he make an appointment with the Heart Centre to get his ICD re-programmed with an extra feature. The reply included the date and time of the recorded episode. We later learned that the patient himself correlated the time of the recorded episode with an incident where he was asked to "give it all you got" in a cardiac stress test in another research project. He later informed us: "This is therefore a situation where I gave myself physically to the fullest. [The physician] said that I could safely exercise. The question is now: Can I?" (man, age 65's logbook entry in myRecord, April 2010). In this way the bioanalyst's reply supports his own interpretation and makes him actively question his treatment and the physician's advice.

3.3.5. Use of Medicine List

The paper-based medicine list was an intricate part of the interpretation practice in the collocated setup. The patient would carry the folded piece of paper with the medicine information to the Heart Center and this information would be included in the interpretation process. In the telemonitoring setup the healthcare professionals lack access to the medication list. In myRecord we designed for patients to create, update, and approve an online shareable Medicine List with the ambition to test whether this list could support the healthcare professionals in their interpretation practices. Surprisingly, we found that the bioanalyst purposefully disregarded the Medicine List doing the evaluation. In one case, a patient (woman, age 60) was initially classified in Group A, but in myRecord she flagged attention. In the free text field she explains that her medicine was changed by her local physician. She also provides a full list of her current medication. The bioanalyst does not even glance at the Medicine List but immediately records a audio message: "[...] Hi [the woman's name],

it's about the comment you wrote in myRecord about your medication. I can only say yes/OK for it, since we do not interfere with what they do in research [another medical research project]." (bioanalyst, dictation in myRecord, April 2010). In this way, the bioanalyst explains the responsibility related to medication changes and does not use the information in the list. During the intervention the bioanalyst explains about the use of medication informations:

"So, our problem right here is that, we type all [medication information from the patient's medication list] into [a medicine management system] and then we go to the ICD Registry [national online ICD/pacemaker information] and type it again. (...) If the patient is physically present we always ask: 'what medication do you take?' The problem is that we don't [type in medication information] in the [telemonitoring setup], because we can't telephone each patient and ask about their medication. We [bioanalysts in the telemonitoring setup] don't use [medication information] for anything; it is only for physicians that might need [the information]" (bioanalyst, observation, April 2010).

Here, the bioanalyst explains how the telemonitoring setup changed the practice surrounding medication, by re-organizing practices to disregard medication information because of the lack of access to this type of information. The absent patient caused absent medication information, thus forced the bioanalysts to skip the task of updating the national ICD registry. We found that in the telemonitoring setup, it was only the cardiologists who were interested in medication information, where in the collocated setup it included the bioanalysts. However, in the few cases where the healthcare professionals had access to medication information using myRecord, we did not see any cases where the cardiologist asked for the medication list. However, this might be due to the previously changed practices caused by the telemonitoring setup, where the cardiologist had learned to do without such information, since these are no longer available. More studies are required to determine whether medication information is essential or not during telemonitored interpretation practices.

4. Discussion

In our study, in the same way as Bardram et al. [15], we investigate the transformed practices caused by telemonitoring, and as Bardram et al., we see how the rich collocated conversations between the patient and the healthcare practitioners were reduced; not to asynchronous messaging as Bardram et al. found, but to one-way communication of sending bodily device data and getting a short reply. The previous collaborative process of interpretation in the collocated setting was reduced to data transmission. However, whereas the latter study [15] found that the patient became more involved in the interpretation of the data, our study showed the opposite. Namely, our study showed that the patient became passively disengaged and more distant from the data interpretation process. This disengagement due to the socio-technical setup of telemonitoring affected the ICD data interpretation practice by neglecting the patient's vital role in general, and in particular, the patient's own interpretation of the general condition and the ICD data. Interestingly, we found that that

the disengaged patient was problematic for the healthcare practitioners, because they lacked essential information for interpreting the data, in particular, for the Group B patients, where the available device data was not sufficient to determine the appropriate action. Our design intervention was designed specifically to deal with this problem, bringing additional contextual information to the healthcare practitioners supporting the ICD data interpretation and re-introducing the patient as a collaborative partner. In the evaluation of the design intervention, we found that myRecord did provide additional useful contextual information enabling the decision for appropriate action for the Group B patients. In this way our design did make the work of interpretation more collaborative; however, we question if this re-designed practice (where the patient contributes with additional information) can be labelled as collaboration or as mere transmission of more data?

If we look at the three different levels in which the patient can provide the additional contextual information within myRecord, one could argue that simply flagging attention or filling out the medical categories are practices where the patient simply delivers more data and not an act of collaboration. Collaboration requires that the actors are mutually dependent in their work [1], thus the question is whether the patients and the healthcare practitioners are mutually dependent on each others' actions? Given that the healthcare practitioners were able to conduct their work before the introduction of myRecord without any involvement of the patient beyond providing the bodily data, one could argue that the patient and the healthcare practitioner were not mutually dependent in their work prior to myRecord. However, with the introduction of myRecord, when the patients flag attention, they change the state of their individual work (their involvement in the data interpretation is not simply providing bodily data). The question, then, is whether this individual activity (flagging attention) also changes the state of the work for the healthcare practitioners and thus the common field of work? During the evaluation of myRecord we saw how patients originally categorized as belonging to Group A (sufficient information) were re-categorized to patient Group B (deficient information) by the bioanalyst as a result of flagging attention, as was the case with the ten patients who chose not to flag attention. This points to how even a small amount of information can change the state of the common field of work. The collaborative aspect of the common field of work (the ICD data interpretation) is thus re-introduced by our design intervention. However, it was also clear that the patient's active role in the new transformed collaborative practice comes in different forms depending on the level of involvement the patient chooses.

At the lowest level of involvement the patient simply flags attention, which is used by the healthcare practitioners to re-evaluate whether their initial categorization of the patient is accurate. Then, at the second level, the patients have the opportunity to express, using their own language, what they think might be relevant for the ICD data interpretation practice, and at the third level, the patients volunteer their own diagnosis of their condition, applying the standardized medical categories. There is no question that all of these levels of involvement change the state of the common field of work, therefore they are all part of the collaborative practice. How-

ever, we saw how the collaborative practice took different forms.

We saw that, in the case of Group B patients (where the ICD device data are insufficient to make a decision), the additional contextual information provided by the third level of information (the standardized medical categories) was sufficient for the healthcare practitioners to make a decision, as in the case of the patient (man, age 61) who used the medical symptom categories. In this way, the collaborative interpretation practice ends quickly with a decision of appropriate action. While this form of collaboration was intended by our design, we also detected two other intriguing forms of collaborative activities caused by our design: inclusion work and self-diagnostic work.

Inclusion work is work that healthcare professionals do when educating the patient outside of training sessions, such as comforting and reassuring patients about their abilities to master new technology, thereby turning potential non-users into users [18, p. 280]. Inclusion work for ICD patients involves telling the patients how to react to different alarms set off by the ICD, for example fluid or battery alarms. In the collocated setting, inclusion work is an embedded part of the collaborative interpretation that unfolds in joined conversations with the patients at the Heart Centre. However, in the distributed telemonitoring setting prior to the introduction of myRecord, inclusion work disappeared from the ordinary activities. With the introduction of myRecord, we unexpectedly found that inclusion work was re-introduced, for example, in terms of explaining ICD battery state. Here, based on her experiences with patients' misunderstandings, the healthcare practitioner translated the ICD battery state, "at least three months," into understandable language for the patient within an audio recording using myRecord.

Self-diagnostic work is the work involved when the patient is actively engaged with the diagnostic work usually done primarily by the physicians. This type of work serves to distinguish and identify how particular bodily experiences can be interpreted. When the patients are asked to apply the standardized medical categories within myRecord to determine the current condition of their health, they are asked to take part in the diagnostic work. We saw that patients took this task seriously. Besides providing additional contextual information, they also played an active role using myRecord and asked the healthcare practitioners direct questions, for example, to confirm their own interpretation of a stopped alarm or to use the ICD data to question physicians' recommendations.

We argue that the socio-technical setup of myRecord re-introduces the critical role of the patient, thus bringing back the collaborative aspect of ICD data interpretation practices. The consequence of this re-introduction is that the patient is situated as a diagnostic agent and the two processes, interpretation of general condition and patient's own interpretation of condition and ICD data, which were otherwise lost in the distributed setting, reappear in the telemonitoring setting through the design intervention with myRecord. By intervening, we probe into ways of re-positioning the patient as a reliable and valuable diagnostic agent, thereby challenging the dominant logic of care [33] while still maintaining the benefits of remote monitoring in terms of saving time for patients and healthcare professionals. Patients are re-introduced as technologically empowered actors with increased expecta-

tions toward taking part in their own treatment. The patients become actively engaged and are expected to take on an increased workload to realize the full potential of the new design. The evaluation showed that the majority of the patients were willing to take on that workload, especially in situations where they saw that as a strategy for receiving more elaborate feedback from the healthcare professionals' interpretation. Patient-generated content makes for a new practice that renders patients more responsible, and consequently more disciplined actors [34], with increased expectations of active membership attached. At the same time, however, it raises questions still not fully answered, neither in our study nor in the literature, about the responsibility and practicalities of healthcare practitioners to act upon critical symptoms provided through designs like myRecord in a timely manner.

5. Conclusion

Earlier studies [18] show that including the patient in telemonitoring practices is vital; however, the patient needs time and effort to become a skilled, active, and responsible participant able to engage in the interpretation process. When the patient is reduced to representations such as images and graphs, the essential cooperative potential between the healthcare practitioner and patient when interpreting the ICD data collocated disappears. The invisible work of the patient involved in interpreting practices is missing. While the reduced representation might be adequate in some situations, it seriously "disables" the data interpretation process in situations of uncertainty. Here the patient's active role as diagnostic agent is needed so that the representation becomes adequate "to speak" for the patient [19]. We designed myRecord to re-introduce the patient in the interpretation process by providing the patient the opportunity to add contextual information to the partial representations captured and measured by the ICD-monitoring system.

New technologies involved in the monitoring and treatment of chronic heart patients with ICDs make it possible to transform the previously local practices of interpreting ICD data into a globally distributed activity where the patient and healthcare professionals are geographically distributed. However, before embracing these new opportunities, we must examine the existing local practices of interpreting ICD data, ensuring that the new technologies enable rather than constrain these practices. Based on our observational study, we conceptualize the ICD data interpretation practice as three entangled processes: (1) *interpretation of numbers*, (2) *interpretation of patient's general condition*, and (3) *the patient's own interpretation of general condition and ICD data*. Moreover, we found that the current telemonitoring system only supports the first process of interpretation, leaving out the two others.

Our socio-technical design intervention re-introduces the patient and takes the collaborative aspect of the interpretation practice seriously. We saw how our design intervention managed to include the two otherwise lost processes of ICD data interpretation, as well as how the patients went from passive bodily device data sources to active diagnostic agents. We believe that this approach to increase the participation of the patients in telemonitoring situations forms the future for

Summary points

What was known before the study:

- Telemonitoring transforms healthcare practices in unanticipated ways
- With the increased use of modern ICDs (implantable cardioverter-defibrillator) the practice of telemonitoring emerges.
- In order to understand how telemonitoring practices influence the interpretation of ICD data, we need to investigate practices in both collocated and distributed settings.

What the study has added to the body of knowledge:

- An illustration of the socio-technical transformation of work practices during the interpretation practices of ICD telemonitoring.
- An understanding of the three essential entangled interpretation processes involved in ICD telemonitoring.
- Illumination of how two of these processes are neglected in the current telemonitoring setup
- How to design for patients as diagnostic agents in collaborative telemonitored interpretation
- Insights into how the design of a collaborative socio-technical information technology can turn patients from passive sources of bodily device data into active diagnostic agents.

improving telemonitoring practices. Previous studies of what gets lost in the design of telemedicine point to the invisible, however essential, work of combining various information artefacts into a coherent whole [18,19]. In our design intervention, we try to bring back the invisible work done by the patients during ICD data interpretation, thus taking seriously what was otherwise lost in telemonitoring.

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The Participatory Patient

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ABSTRACT

This paper introduces the concept of the “participatory patient” as a vehicle to promote attention to patients’ dual enactment of participation on participatory design (PD) projects in healthcare. By an empirical case-story from an ongoing PD project in healthcare, I illustrate the relationship between a patient’s work on the project as a co-designer and his work of being a patient using a prototype. I conclude by arguing for the importance of being aware of the ways in which patients inscribe patient work and non-work and thinking of what kind of working or non-working patients it implies.

INTRODUCTION

The role of patients as active participants in healthcare has since the beginning 1990’s been subject to increased attention in healthcare practice, education and research (Funnell and Anderson, 2003; Salmon and Hall, 2004). The discourse revolves around the patient as an active agent in managing illness and healthcare and posits the active involvement in treatment procedures as generating greater improvement in health and patient satisfaction (Street Jr, et al., 2005). Patient empowerment has been the overarching concept of the patient-centric healthcare philosophy. The idea of empowering patients aligns very well with the theoretical and political foundation of PD. Strategically, PD is guided by two types of values; a) the ambition to democratize the workplace by considering proper conditions for user participation and b) ensuring participants’ existing skills or tacit knowledge as a resource in the design process (Ehn, 2008).

On the CITH-project (see acknowledgements), from which I report, we involve a group of heart patients in a diverse set of design and use activities. Through a modified version of collaborative prototyping (Bødker and Grønbæk, 1992) we prototype several versions of a web-based personal health record. As a means to ground the design in the patients’ health related activities we take great effort in not only letting them design features of the prototype directly but also indirectly by studying their work of being patients with and without the use of prototype. In this way we ensure that they and we get to experience the prototype as integrated in their healthcare and actual use. Bødker and Grønbæk (1992) call it envisionment and argue for the opportunity to uncover unarticulated aspects of users’ work and dynamic aspects of the future application.

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In this paper I introduce the notion of the participatory patient with the purpose of highlighting consequences of letting patients not only design but also use the prototype. As such, the participatory patient plays out and shapes the intimate relationship between current and future patient work.

BACKGROUND

For the purpose of examining the relationship between patient involvement in healthcare with their participation on a PD project I review participation according to how patients are involved in their disease, what they do to manage it and by which means they succeed in doing so. I end this paragraph with a brief introduction to PD’s attitude towards user participation.

One strand of research in medical care and patient education concerns the relationship between physician and patients. In some studies this relationship is examined as a co-located phenomenon with a focus on the clinical setting and the characteristics of the dialogue (Street Jr, et al., 2005). Active forms of patient participation are represented by the patient communication behavior: Asking questions, expressing concerns and being assertive. Street and others argue that patients in this way interject their perspective into the interaction and that it can have a powerful influence on the physician’s behavior and decision making. According to Roter (2000) it is the medical dialogue through which patients’ values are explicitly exercised in the relationship-centered medical paradigm.

Unruh and Pratt (2008) describe in what many ways patients participate in their healthcare by doing invisible but yet important work. They show how one cancer patient becomes a de-facto medical information courier from one institution to another whereby bridging inter-institutional care. They introduce the concept of “state awareness” to accentuate how cancer patients struggle to obtain information about their current health status. The lack of information stimulated emotional distress, especially when information was expected. The patients in the study responded in ways that put a pressure on healthcare staff resources and created inefficiencies at the treatment center.

In the same line of research, Oudshoorn (2008) similarly builds on Star’s, Strauss’ and others’ (Star and Strauss, 1999; Strauss and Fagerhaugh, 1997) framing of patients’ invisible work. In doing so she develops the concept “diagnostic agent” to capture the new type of invisible work that heart patients get to do with the introduction of new telemedicine applications. By a case study of heart patients’ use of an ambulatory ECG recorder in the Netherlands she foregrounds how this reconfiguration produces patients that are more active and

responsible participants in the diagnosis of their heart problems. Such a perspective is pertinent to sociologists of science, technology and society studies (STS). Researchers herein have demonstrated how delegation of work is a major characteristic of the introduction of new technologies and how it often leads to redistribution rather than a reduction of work. This kind of patient work could be categorized as “homework” (Grøn, et al., 2008) which in turn emphasizes changes in the organization of healthcare. Self care and monitoring at home necessarily creates a paradigmatic shift towards increased patient responsibilities and demands on their management of homework and the implications it has on their social commitment.

In PD the concept of the participant, or many times the user or worker, has its roots in a political marxist democratic ideal. The classic strand of PD advocates full participation from the users i.e. the requirement of training and active cooperation (Greenbaum and Kyng, 1992). Kensing and Blomberg (1998, p. 173) illustrate participation on PD projects as a spectrum where participants in the one end is limited to “[...] *providing designers with access to workers’ skills and experiences. The workers have little or no control over the design process or its outcome*”. In the other end of the spectrum participants take active part in analysis of needs, design, selection, evaluation, and implementation. Participation on PD projects differs tremendously but active work by the users, workers or patients is a premise for both design and research.

METHODOLOGY

As a strategy for extensive user involvement on the CITH project we apply prototyping as a way to explore by intervening in the space of problem and solution of patients’ and their healthcare professionals’ everyday practices. On the project, the patients design either explicitly or implicitly. Either they a) co-design and directly shape functionality of the prototype or b) they use the prototype as part of their treatment, which we, sometimes in collaboration with the patients, translate by analysis and design and implement in the prototype. This iterative move between design and use necessarily makes the participating patients as co-interpreters and creators of (a new class of) patient work. Before use, they and we, together and separate, inscribe some notion of intended use by designing. At this point the definition of patient work is not enacted but is merely a prescription of what work the patient might do. After design, or when the participating patients use the prototype as part of their treatment, a description, as opposed to a prescription, of patient work is enacted.

Redström (2008) speak of this relationship as acts of defining use. He differentiates between ‘defining use through design’ and ‘defining use through use’. He makes the distinction to argue in favour of questioning how and when use is defined instead of who i.e. the user or the designer. In the following case, I take on Redströms argument, moderated for the purpose of illustrating when and how a patient enacts the relationship between current

work and future work. Use therefore translates to the participating patients’ actual work using the prototype. Design translates to the patients’ explicit prescriptions of work or their implicit prescriptions in the shape of our translated descriptions of acts. As a way to investigate the relationship between patients’ work of participating in their treatment and the work they do on the project I will use Redström’s terminology as a structure to present the empirical case of a participatory patient, MR. Norman.

THE PARTICIPATORY PATIENT

In what follows, I develop the notion of the ‘participatory patient’ from an empirical case of Mr. Norman, age 65 (anonymized). He is a heart patient with an ICD (advanced pacemaker) who participates on the CITH project.

Case introduction: Mr. Norman, aged 65

Mr. Norman is in many ways an ordinary 65 year old man who lives with his wife on the top floor of a well maintained apartment building in central Copenhagen. He is employed as a senior chief in a government agency, has two adult children and occasionally plays an 18 hole round of golf with his friends (information from logbook entries in the prototype, April 2010). After a match of golf in 2005, where he could not carry out all holes, and after a few nights, where he had to sit up on the couch to get up, his doctor admits him to the hospital with suspicion of blood clot in the lung. Soon after he is diagnosed with a heart disease and gets a modern ICD device implanted. The device is part of a telemedicine practice, which enables Mr. Norman to transmit ICD-monitored data wirelessly to the bioanalysts for ICD data interpretation at Copenhagen University Hospital’s Heart Centre (telemedicine setup). At the same time he receives medical treatment at another local hospital.

Four years later Mr. Norman accepts and takes part on a PD research project, CITH, where he, besides doing patient work as usual, engages in various activities of design and use of a co-developed prototype. The prototype under development is essentially a web-application through which the participating patients can communicate with healthcare professionals and other patients, keep track of health related appointments and access various forms of information related to their disease and health status. In medical informatics similar applications are often discussed under the name of a personal health record. In the following I will present design and use of three types of functionality being what we call ‘Logbook’, ‘Transmission’ (of ICD data) and ‘Medical Consultation’. These functions are integrated with healthcare professionals’ work practice.

Conceptualizing patient work through design

After early participant observations of medical consultations, interviews with patients in their homes and three design workshops, we designed and developed functionality in the first version of the prototype, which twelve patients (including Mr. Norman) used in respectively eleven and fourteen weeks. We then visit Mr. Norman in his home, review his past use of the prototype and co-design new functionality of a second version of the prototype. Among other things, he describes his

practices around medication and explains: “[...] I always need to bring my own list of medication because they [the healthcare professionals] never have an updated list of what medicine I take” (transcription of co-design session, February 2010). He also adds to a discussion about a possible medicine list in the next version of the prototype: “[...] Yes, a medicine list in [the prototype] would be really good because then I can just refer to it online and I don’t need to worry about remembering the newest list [...]” (ibid.). As a participatory patient Mr. Norman describes his contemporary work of keeping an updated list of medicine and emphasizes the importance for it to be sharable with the healthcare professionals who treat him. He explicitly contributes to the re-design of a future socio-technical practice in which his work of informing about his medicine becomes partly delegated to information technology.

Later in the same session we discuss how Mr. Norman could take on a more active role when making an ICD transmission. The idea we present to him is similar to the sharing of the medicine list in that Mr. Norman potentially would write down experienced symptoms, select appropriate medical categories and ask questions when he makes a transmission of ICD data. He adds to our design proposal: “But, then it [the reply area from the Heart Centre in the prototype] should be connected with what you write over there [text input area in the prototype] – because if I write something as for instance a question and say: “The 16th I had such and such or something I did not understand, then I would probably expect an answer on that matter” (ibid.).

Here Mr. Norman adds a layer to the design of the prototype by spelling out his expectations of receiving improved information on his health status. In the conversation he explains what qualities he sees in making the transmission into a dialogue where he has the possibility to question and describe symptoms and experiences and in return get a more informed answer of the ICD data interpretation. In short, he negotiates possibilities of and prescribes a more active patient by explicitly asking for possibilities for more informed communication when he makes a transmission.

Conceptualizing patient work through use

After the co-design session with Mr. Norman and various other design and analysis work we include a way for patients to communicate experienced symptoms and questions in relation to a transmission (of ICD data) and a medical consultation. Included herein is a sharable version of patients’ own medicine list. We agree with his Mr. Norman’s cardiologist at the local hospital to try out the ‘Medical Consultation’ functionality and with the bioanalyst at the Heart Centre to try out the ‘Transmission’ module. The evening before the medical consultation at a local hospital Mr. Norman logs on to the prototype, corrects and “approves” his medicine list by clicking the Approve-Medicine-List button. He also writes questions for the cardiologist in a short and listed format and confirms his preparation: “My general condition •what can I do in the future? Golf, gym, etc. •My chest pain, see the logbook note dated 10.3.10 • The “tugs” I experience, the same note. •Dizziness, when I

stand up from sitting •My fatigue (I fall asleep easily if I’m “just sitting” in a chair) •Is my case hereditary (I have two sons at 37 and 35 years - and grandson - soon grandchildren)?” (Logbook, April 2010).

At the consultation the next day the cardiologist spends a minute reading Mr. Norman’s medicine list and questions on a printout. The consultation begins and a couple of minutes into the dialogue the cardiologist looks at the printout and says: “I have the list here.. There are at least something with some symptoms, something with some tugs, dizziness and fatigue. And I would say, let’s take it at the same time because they belong together” (transcription of video of medical consultation, April 2010). In this example Mr. Norman’s work of preparation by writing a list of questions prove to take on a central role in shaping the meeting. Throughout the consultation the cardiologist uses the list to talk about Mr. Norman’s questions because, as the cardiologist explains later, to make sure that he gets around all of Mr. Norman’s issues. The cardiologist moreover makes use of the Mr. Norman’s list by reading the printout while dictating a resume for the hospital’s medical record.

In relation to a transmission of ICD data to the Heart Centre Mr. Norman uses the prototype to comment on his health situation, create a medicine list and ask questions to the bioanalyst at the Heart Centre. He makes a transmission and logs in to the prototype where he indicates that there are changes in his health status. He describes his interpretation of own condition and asks whether it is correct that he experienced an episode on [exact date].

The following day the bioanalyst at the Heart Centre investigates the ICD data while Mr. Norman is at work. When combining her interpretation of the data with Mr. Norman’s comments she decides to dictate a reply to him using the prototype. She explains to Mr. Norman that the ICD has recorded one episode on [exact date]. Some days later, Mr. Norman explains in a logbook entry how he correlated the time of the ICD device’s recorded episode with an incident where he was asked to “give it all you got” in a cardiac stress test in another research project. To this he notes in his logbook: “This is therefore a situation where I gave myself physically to the fullest. [The physician] said that I could safely engage in physical exercise. The question now is: Can I?” (logbook entry in the prototype, April 2010). This response shows how the advent of improved state awareness has created more work and worrying for Mr. Norman.

DISCUSSION

By letting Mr. Norman enact the relationship between design and use, he directly and indirectly participated in inscribing the work of an active and involved patient. He has negotiated a different means of asking questions, expressing concerns and being assertive in medical consultations. Mr. Norman has succeeded to create a way to obtain increased state awareness of his ICD and developed a way to remotely share his current medicine list. In short, he has actively inscribed an active participating patient into the workings of the prototype.

What has surfaced, in the conceptualization of patient work through use, is that the prototype prescribes more and different work by patients. In the case of a medical consultation, heart patients using the prototype are in the future bound to spend time at home in front of a computer and use the prototype to prepare for consultations. The prototype additionally prescribes work of reviewing the medicine list in advance and makes the patient decide from home what is relevant to communicate for each drug. In other words, the responsibility of working out a complete medicine list has been formally delegated to the patient. The possibility to remotely question and achieve increased information about ICD data, prescribes patient work of improving diagnostic skills and developing ways to deal with information that is not easily understandable. The advent of the prototype, integrated into the heart patients' healthcare, formalizes current patient work and prescribes new types of patient work such as diagnostic work. Patient homework is no longer invisible but very visible since it has been hardcoded in much functionality of the prototype.

What the case does not reveal, is the application of the prototype over a long period of time. As demonstrated, actively participating patients, such as Mr. Norman, are empowered by the tool in some ways. But what the prototype does not prescribe is non-work or non-use. This, I would argue, is another means of empowering patients – to take into consideration and inscribe means for patients to be less active and participating patients.

CONCLUSION

By the case of Mr. Norman I illustrated the ways in which a patient on a PD project, directly and indirectly, participated in inscribing an empowered patient. Increased involvement in his healthcare implied more homework and different kinds of patient work surfaced. A demand of more diagnostic skills and increased responsibility moreover became apparent in the workings of the prototype. As a concept in PD, the participatory patient should promote attention to patients as particular users or workers and force organizers of PD projects in healthcare to think of how and what kind of participation the involved patients collaborate in inscribing.

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DESIGN INTERVENTIONS AS MULTIPLE BECOMINGS OF HEALTHCARE

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ABSTRACT

Research on design of IT traditionally treats the production of scholarly knowledge and the design of new systems as related, but separate processes.

We propose the fruitfulness of practicing a closer relation informed by interventionist design research (appreciating a problem through attempts at solving it) and actor network theory (reality is enacted and constructed through our engagement).

Through three concrete design interventions with cardiatric healthcare, we illustrate how diverse agendas of sociological inquiry and practical design considerations are intertwined and come to enact healthcare in specific ways. We suggest this as a *strategy of multiple becomings*, wherein assemblages of patients, health professionals, diseases, information technology, prototypes, and design researchers together perform shifts between promoting new practical design solutions and raising novel questions on the socio-material complexities of healthcare.

INTRODUCTION

When the cardiologist-patient consultation was coming to an end, the design researcher intervenes to propose a new design-research concept in *myRecord* – a web-based prototype of a patient-centric health record.

Design researcher: “*There is one more thing. We’ve created what we call ‘assignments’, which are a little experimental, but in your discussion with Karl [heart patient] you indirectly ask him to do some tasks – that he must keep an eye on this and that – so, what should he write down [in myRecord]? ”*

Cardiologist: “*Oh – Yes, okay [...] Karl, we’ve talked about that you need to find out how your breath is. This means that you every day have to go out on the street and walk until you need a break. Then it’ll say [in myRecord]; Monday 50 m., Tuesday 50 m., Wednesday 45 m., Thursday 70 m. – anything [...] ”*

Karl strives to follow the cardiologist’s suggestions and almost daily for three weeks he records his weight and blood pressure in myRecord (picture 3). However, as the logbook in myRecord reveals, he is too weak to measure his walking distance. As we elaborate further in the case of ‘Patient Homework’, this snippet is meant to illustrate how design interventions enable us to enact entanglements of sociologically-inspired inquiries in healthcare practice and explicit and change-driven promotion of new design-research solutions for improved healthcare. Through design interventions new relations are performed in assemblages of healthcare professionals, diseases, information technology, prototypes, design researchers, and theoretical conceptualizations and themes from IT research in healthcare. We suggest that conventional approaches to knowledge production within the primary fields that do IT (design) research in healthcare, such as Computer-Supported Work (CSCW), Information Systems (IS), and Participatory Design (PD) can be fruitfully complemented by more interventionist approaches as practiced within contemporary design research (Medical Informatics is focused on evaluation of IT and less on the design process, thus not included in this positioning). By three cases of design interventions we engage multiple interests within interventional assemblages and show how new relations are performed between concrete

design proposals and more theoretically conceptualized inquiries. We report from a PD project entitled Co-constructing IT and Healthcare (CITH), engaging heart patients and relatives, health professionals and us (design researchers) for nearly three years (2008-11) to explore and experiment with re-organizing current work practices through the design and use of seven hi-fi versions of myRecord ('Egenjournalen' in Danish). myRecord is essentially a prototype of a personal health record (Kaelber et al., 2008) – a patient-centric, collaborative, web-application that enables heart patients to produce, collect and share health related information with health professionals and other patients in their network (for details on CITH and myRecord see Andersen et al., In press).

IT (DESIGN) RESEARCH

Practicing interventions are not new to PD, CSCW, IS, or human-computer interaction (HCI). However, we find that design interventions as performative arenas for explicit instantiations of theoretical conceptualizations and themes are not thoroughly discussed. By employing design interventions we argue that a closer relation between, not only research and design but multiple logics come into being. Early studies at Xerox PARC (Blomberg et al., 1995; Suchman et al., 1998) as well as work coming out of the Scandinavian approach to systems design (Bødker and Grønbæk, 1992; Mogensen, 1992; Kensing, 2003) took on experimental and interventionist approaches to design and research. Influences from action research (Checkland and Holwell, 1998) and intervention theory (Argyris, 1970) pushed for intervention, which is much appreciated in PD today. In PD, methods and techniques from design practice are employed to support a combined research and development process. However, PD is mostly concerned with research on methods and techniques for the practice of participatory and democratic design and contributions rarely emphasize methodological discussions. The episteme of classic PD work could be argued as subscribing to Schön's (1983) reflective practicum, wherein problems are made intelligible only through attempts at solving them.

In CSCW, ethnography and qualitative methods are highly developed and the debate on workplace studies' role in IT design has been heavily debated (cf. Crabtree et al., 2009; Dourish, 2006; Plowman et al., 1995). It is widely argued that detailed analyses of work and technology-in-use create 'insights', 'implications', and 'recommendations' to *inform* system design (Plowman et al., 1995). A view that is also reflected in Crabtree et al.'s critical argument favouring ethnomethodologically-informed ethnography in systems design: "*Our purpose is to inform systems designers – i.e., those parties who are actively involved in the development of computing systems and applications [...]*" (2009, p.879). The practice of doing research (ethnographical work) and designing IT are traditionally kept as separated processes in studies that actually argue for the promising results of integrating research and design of IT (Luff et al., 2000; Crabtree et

al., 2009). While the proponents of joining ethnographic practice and design are increasing (Wolf et al., 2006; Halse, 2008; Karasti, 2001; Simonsen and Kensing, 2005; Zimmerman et al., 2007), the debate on the role of ethnography in design of IT continues (Button and Harper, 1996; Crabtree et al., 2009).

Within IS, action research and design science seek to accomplish change relevant to practice by proposing a closer relation between the study of organizational work practices and the design and implementation of relevant IT artefacts (Hevner et al., 2004; Baskerville and Wood-Harper, 1996; Checkland and Holwell, 1998). However, the heritage from behavioural science combined with a wish for hypotheses-driven rigour renders the process of designing secondary, in that the artefact comes to play the role of a utility that (only) "*allows [for] many types of quantitative evaluations [...], including optimization proofs, analytical simulation, and quantitative comparisons with alternative designs*" (Hevner et al., 2004, p.77). Karasti (2001, p.211ff) critiques these disciplinary dichotomies i.e. descriptive vs. prescriptive, present vs. future, understanding vs. intervention and argues for a more "*appreciative intervention [which] calls for envisioning images of future system and context through a recognition of presence and change intertwined in the existing ways of working.*"

In design research and increasingly in HCI, design practice is argued as a fruitful vehicle to drive research inquiries (Wolf et al., 2006; Zimmerman et al., 2007). Proponents of critical design (Gaver et al., 2004) use designed artefacts to 'instantiate' philosophical ideas whereas the design process becomes a necessary mode of inquiry. In this paper, we subscribe to a design research program and propose design interventions as situations of enactment with opportunities to live out and explore change potential as well as "*open new ways of conceiving the world*" (Halse, 2008, p.2). We claim that in one and the same poignant moment, understanding and designerly creation co-exist as inseparable modes of socio-material knowledge production.

STRATEGY OF MULTIPLE BECOMINGS

Koskinen, Binder and Redström (2008) review how researchers integrate design experiments in their research inquiries. Through three categories, *lab*, *field* and *gallery*, they describe how "*design researchers have developed several approaches that integrate design-specific work methods into research.*" They make a division along the lines of traditional scientific methodologies and the arts, and argue that design research has been practicing extensions and sophisticated variations to more established institutional approaches to research. In later contributions the three categories converge and this could be seen as a movement towards design research achieving a degree of maturity, with less need to honour standards in other disciplines. Mattelmäki and Matthews (2009) expand this point and focus on the practical concerns of how those differences play out in

a diverse set of ways. They recognize that Frayling's notion of *research-through-design* unites many and stress that it should not be seen as a method, but rather as a family of heterogeneous approaches to design research (2009, p.9). Their affinity lies in considering the design project, process or artifact as fundamental to the research contribution.

With this paper we propose design research as a making of explorative assemblages of not only 'design' and 'research', but multiple entanglements of patients' and health professionals' practices, diseases, information technology, prototypes, and design researchers. In particular, as we sketch out below, we are inspired by later developments in actor-network theory that treats 'being' as inherently performative and holds multiple interdependent realities (Law and Hassard, 1999; Pickering, 1995; Barad, 2003).

DESIGN INTERVENTIONS AND MYRECORD

On the CITH project we have engaged an interventionist approach as a way to extend classic PD with a more critical mode of design research-led inquiry. In the outset of the project we sat in on medical consultations, overlooked heart surgery, followed patient referrals in between hospitals, and observed work practices in several cardiac wards. We interviewed secretaries, nurses, doctors and bioanalysts on three related hospitals and visited patients and their families in their homes. A couple of months into the project, we began to put more emphasis on introducing proposals and discussions of premade and in-the-moment ideas of (IT) solutions as well as carrying out participatory design workshops. Alongside these activities we studied the literature on IT research in healthcare, e.g. (Mol, 2008; Berg, 1997; Pratt et al., 2004; Aarhus et al., 2009), and discussed how we could integrate a mode of inquiry that would add to the academic discourses found in the literature, but also how we could enact them concretely in the process.

This endeavor was particularly enhanced when we, a year into the project, introduced action cycles and turned the project into a cooperative prototyping process of a patient-centric web-application. It kick-started a long range of design interventions with myRecord wherein we engaged different health professionals and heart patients in various situations and locations. What moreover followed was many internal meetings and workshops where we inscribed theoretical conceptualizations and themes in myRecord through discussions and co-sketching interactions and wireframes. Typically, as continuations to ongoing dialogues with patients and health professionals we carried out co-design and use sessions at patients' homes. We then followed patients to consultations as observers of use but also as design research advocates enacting explorative and critical inquiries. The interventions, then, became a space for the simultaneous enactment of multiple logics, interests, and ideas. Our strategy of applying design interventions became instantiations of what Law (2004) calls *method assemblages*. By staging situations

of (creative) use in realistic healthcare situations we were able to intervene and cooperatively interweave the current with enactments of new instances of healthcare. Moments, where not only relations between practices of 'design' and 'research' were performed, but multiple becomings of healthcare (Mol, 2002). A lot of work went into preparing for the interventions to allow for the otherwise absent (in the situations) to possibly become present. Priority was put on loading each intervention with the possibilities to enact patients' and health professionals' wishes as well as to enact and explore questions such as 'how to make patient participation a resource in diagnostic work?' and 'how to support patients' invisible work of bridging interinstitutional care?' (cf. Unruh and Pratt, 2007).

In the following, we present three cases of design interventions with myRecord in cardiatric healthcare, to show how an interventionist approach can be employed as means to enact and inquire into different healthcare practices together with empowered patients.

CASE I: MANAGING BY CONCEALING

From our fieldwork on medical consultations we learned how precious time is spent at each meeting on 'getting to the point'. During the consultation, the physician and the patient work together to reach a shared understanding of which issue(s) should be made central to the consultation, and thereby the diagnostic work. The physician is constantly searching for indications of symptoms or other information vital to perform the diagnostic work. Patients often arrive with a set of (not yet fully conceived) questions regarding their health situation and recent experiences. However, once the consultation begins, we found that most patients were overwhelmed by the urgency of the situation and often held back or simply forgot to present their own questions. The different reasons for this ranges from patients forgetting or thinking, "*it's probably not that important anyway*" to feeling self-conscious about the very private character of their concerns (e.g. questions regarding either marital problems or issues of intimacy caused by their disease).

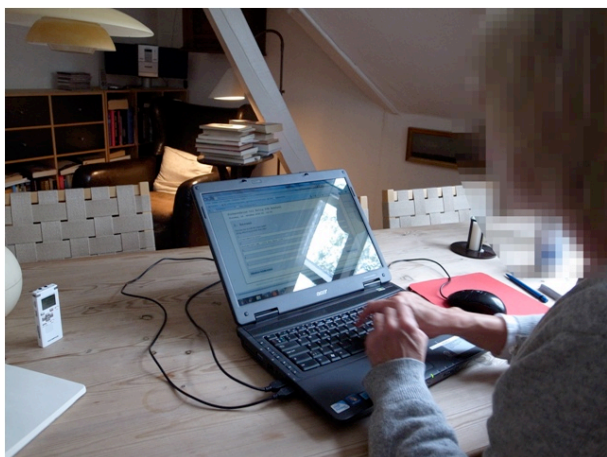
As our understanding of healthcare work practices matured through our initial fieldwork, we were inspired by Berg's (1997) analyses of medical work. In particular, how he characterises the work of physicians. Berg draws on the work of Fujimura (1987), who demonstrates how scientists make research problems doable through the iterative and seemingly mundane processes of continually aligning and reorganizing their work. Berg presents the work done by physicians during consultations as ways of making patients' problems manageable. Work that is "*characterized by the smooth interweaving of 'social' and 'medical' issues*", in which patient-problems are transformed into 'doable' problems (1997, p.137). Berg shows the distributed character of medical work and stresses how "*the transformation of a patient's problem into a 'doable' problem is not a cognitive reconceptualization*

of the patient's case, but a collective achievement of an interlocked assembly of heterogeneous entities" (ibid.). To understand the consequences of this making and becoming of manageable patients we chose to explore the ways in which we could design support for patients to become more manageable for the physicians. From the physician's perspective, this would mean having important information about the patient ready-to-hand (Ehn (1988) and Dourish (2004, p.109) invite Heidegger's notion to inform systems design) before the consultation, including the specific questions and symptoms the patient would like to discuss. We were curious to see how, if at all, the new way of patients preparing for consultations would be useful or just be considered 'more work'.

DESIGN INTERVENTION

The following case illustrates how the interventional setup and the use of myRecord worked as a way to query into aspects of patient manageability, and in particular how the intervention unexpectedly taught us the ways in which a patient take active part in collaboratively making the situation more 'doable'.

Mary (aged 54) and the design researcher, Jonas (aged 30), are sitting in her living room in front of her laptop, preparing for her upcoming consultation at the Heart Centre. Mary is going through the step-by-step preparation which involves answering a set of predefined questions, updating and approving her medication list, and indicating if she is experiencing any of nine specific symptoms.



Picture 1: The design researcher and Mary sitting in her home, preparing for the upcoming consultation

Lately, she has been feeling that her heartbeat is too rapid and is worried about the stabbing pain she sometimes experiences. Going through the symptoms section, Mary initially ticks 'abnormal heartbeats', but then pauses when she is to indicate whether the symptom appears during 'heavy', 'medium', 'light' or 'no physical activity'.

Mary: "Hmmm, I would say... it's this one [pointing at 'during no physical activity']... Not necessarily during physical activity."

Design researcher: "Ok... so, that would mean you experience it at rest?"

Mary: "Not necessarily. It can come at any time. At rest or, for example, when bicycling or walking. But there is no category to capture that..."

Design researcher: "You would need a new category then?"

Mary: "Yeah, because if I state that I experience it during physical activity, then one would think that I have arteriosclerosis... which I do not! It can come at any time. But there is no category to capture that. Then it would easily be misinterpreted if I state that I experience abnormal heartbeats during physical activity –which is when the heart is at work – because that would typically indicate problems with stiffening of the arteries."

Design researcher: "I see. And when you so confidently state that it's not arteriosclerosis, it's because you somehow know and you therefore don't want to indicate it?" (audio transcription, Mary's home, October 8, 2010)

To this, Mary explains how she has been suffering from abnormal heartbeats for a long time, and how she went through an extensive examination a couple of years back, which explicitly concluded no problems with her arteries. And as she states, "If I then indicate it, the treatment will be different." Mary finishes the preparation by selecting the option, 'during no physical activity'.

MULTIPLE BECOMINGS OF HEALTHCARE

As the intervention teaches us the patient explicitly refrains from indicating a specific nuance of an important symptom, whereby she actually ends up concealing information from the cardiologist. Mary's decision is based on her anticipation of what they will probably conclude again, which she knows is incorrect based on her earlier examinations. She specifically engages in the process of making her situation manageable for the cardiologist, but interestingly by taking steps to avoid the consultation from going in a, for her, worthless direction.

As regards to constructive insights for design, we come to understand that the symptom component should be redesigned to allow patients to briefly describe the situation in which they experience a particular symptom. Fixed symptom categories do not always enable the patient to provide sufficient diagnostic information, as we have also learned from Bowker and Star (1999). Most importantly though, with the intervention and Mary's use of myRecord, she starts to manage her physician by performing herself as an essential and guiding part of the diagnostic work, possibly to increase the manageability of her own case.

CASE II: BRIDGING INTERINSTITUTIONAL CARE

When treatment and care is distributed between institutions, as is the case in our study, the patient often becomes an even more central actor in managing and ensuring continuity of care. As argued by Unruh and Pratt (2008) one key task for such patients becomes to *bridge interinstitutional care*, whereby patients work to manage and bring together information from different sources in the distributed network of care institutions. Unruh and Pratt show how this type of work transforms the patient into an *information courier* “shuttling medical information from one institution to another.” (2008, p.38) Having encountered similar situations numerous times during the interventions, we wanted to explore the phenomenon of bridging interinstitutional care further, in a more performative mode. Through several smaller workshops we, and the web developer, sketched and implemented a personal digital document archive (pBox) in myRecord to enable patients to easilier become information couriers. pBox enables patients and health professionals to archive and share documents easily. By storing documents in their pBox, patients ensure health professionals’ contionous access to their documents. To illustrate the use of the intervention to explore ‘bridging interinstitutional care’ by co-enactment, consider the case of Fred who, through the intervention and myRecord, succesfully interrelates the diagnostic work between two heart clinics at different hospitals.

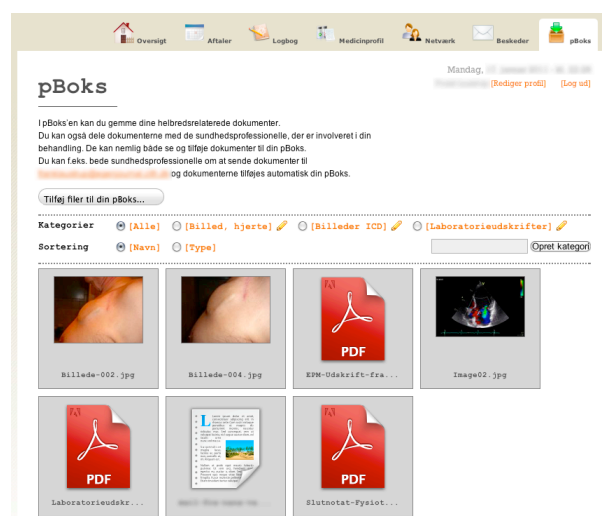
DESIGN INTERVENTION

A week prior to the consultation the design researcher, (Jonas, aged 30), is visiting Fred (aged 57) in his home to promote and encourage him to use myRecord’s pBox (picture 2) to prepare for the upcoming check-up with his nurse. Fred’s wife has joined the conversation and the chat goes on for close to an hour. The design researcher asks Fred if there is anything in particular he would like to discuss with his nurse. While they talk the design researcher pays particular attention to questions or issues that myRecord could support Fred in querying further into. At one point, Fred raises an issue in which he is confused with having received contradictory feedback on two identical scans of his heart done at two different clinics. The two statements report on the state of his heart and its strength, and are both based on echocardiographical scans of his heart. One statement reports he is doing well, in that his ‘heart capacity’ has increased from 10 to 25 per cent. However, the other statement concludes that his heart is enlarged to compensate for the non-functioning area. “*What am I to make of this? How can they be so different, when it’s the same (type of) scan?*” Fred says slightly disillusioned. “*Am I doing progress or not?*”

The design researcher suggests that Fred upload the scan and statement from the other clinic and then use myRecord to raise his question. With help from the design researcher they formulate the questions for the nurse and upload the echocardiographic scan to his pBox together with the e-mail from the other heart

clinic stating the conclusion about the enlarged heart area.

An hour prior to the consultation the design researcher meets with the nurse to explain the setup and hand her printouts of Fred’s preparation and the uploaded images to simulate that myRecord is an integrated part of her daily routine. Half an hour into the consultation the nurse looks at Fred’s preparation, including his questions. They reach his third question, where he correlates the statements from the two clinics, which reads: “*[Name of cardiologist] has scanned my heart and tells me that the well functioning area is enlarged, because it compensates to make up for the non-functioning areas. How does that fit with your recent statement that my capacity has improved from 10 to 25 per cent? (please, see the attached e-mail in my pBox).*” (myRecord transcription, November 2010)



Picture 2: A screenshot of Fred’s pBox in myRecord

After having consulted Fred’s documents, the nurse agrees about the peculiarity of the two different conclusions on the same type of scan. But as she explains, she is legally hindered in obtaining information from the other heart clinic. She therefore asks Fred to obtain the information and then upload it to his pBox, where she is able to access it. Fred shakes his head indicating that he finds the situation a bit peculiar, but agrees to do it.

MULTIPLE BECOMINGS OF HEALTHCARE

With the intervention as arena, prepared by the design researcher’s practical alignment of various actors including the pBox in myRecord, Fred enacts a connection between the two institutions. The new connection, where one clinical facility is confronted with another’s different reading of ‘the same’ scan, concretely come to exist through his performance with myRecord. With the pBox in particular, he establishes relations that did not exist before by bridging two institutions that were not able to communicate. In this way he performs a *diagnostic agent*, as he takes part in carrying out this essential, but often invisible work of aligning and reorganizing interinstitutional information

(Oudshoorn, 2008, p.276). The intervention evolves from the initial inquiry into pBox as a tool to support the enactment of the patient as information courier to an exploration of the patient's role in detecting, preventing and recovering from ambiguous medical situations (Unruh and Pratt, 2007). In this sense the case becomes a concrete example of how responsibility is delegated to the patient. To continue the process of 'finding an answer' to Fred's diagnostic question, Fred not only has to act as a courier "*shuttling medical information from one institution to another*", but has to do more work to connect the two health professionals (institutions) in order to enable collaborative diagnostic work. Moreover, the case also brings us concrete design insights in how to enhance the pBox as a tool for health professionals. Through the situation, we learn that the pBox needs to support subscriptions to and the ability to classify content from a single health professional or institution.

CASE III: PATIENT HOMEWORK

This third case recalls a design intervention in a cardiatric consultation at the Heart Centre between the heart patient, Karl (aged 68), his wife, a cardiologist and a design researcher (Tariq, aged 30). It is the elaborated case from the paper's introductory snippet. Herein, we illustrate how the theoretical concept of 'homework' is made and becomes generative in multiple ways.

Grøn et al. (2008) coin the notion 'homework' to critically accentuate implications of the political shift in the organization of healthcare. They refer to the work issued by the healthcare system, but practiced in patients' homes. Here, patients are increasingly expected to take on more responsibility, which in turn becomes more patient work (Oudshoorn, 2008) and often collides with their everyday lives and unstable health. Field studies and Grøn's argument drew Aarhus and her group (2009) to make it a design principle in their project – not to add to the amount of homework in the development of an 'eDiary' for diabetics. However, others argue that active patient involvement generate greater improvement in health and patient satisfaction (Street et al., 2005). Being aware of this discourse, we deliberately wanted to sketch and implement 'patient assignments' in myRecord to critically inquire into consequences of letting cardiologists give patients' assignments and open up the space for multiple interpretations of homework to be performed. It moreover engaged design inquiries such as; *which features in myRecord are necessary, what data, and which text fields and buttons should we include?*

DESIGN INTERVENTION

In the design intervention, the cardiatric consultation, Karl and a cardiologist are having an intense discussion on whether or not Karl should be re-hospitalized and go through a high risk operation. The day before the consultation, Karl used myRecord at home to prepare for the consultation and the cardiologist read it before they meet and uses it many times throughout the consultation. During 43 minutes they discuss how Karl

experiences shortness of breath and dizziness after the most recent operation. Their dialogue expresses their collective project of deciding on three optional moves, all based on Karl's interpretation of his health condition. After an intense conversation they still cannot make a decision and agree not to do anything, but let Karl stabilize and meet again in two weeks. When everybody stood up and were about to leave, the design researcher (Tariq, aged 30) intervenes and explains the idea of 'patient assignments' and asks if the cardiologist would give Karl a task to complete at home using myRecord.

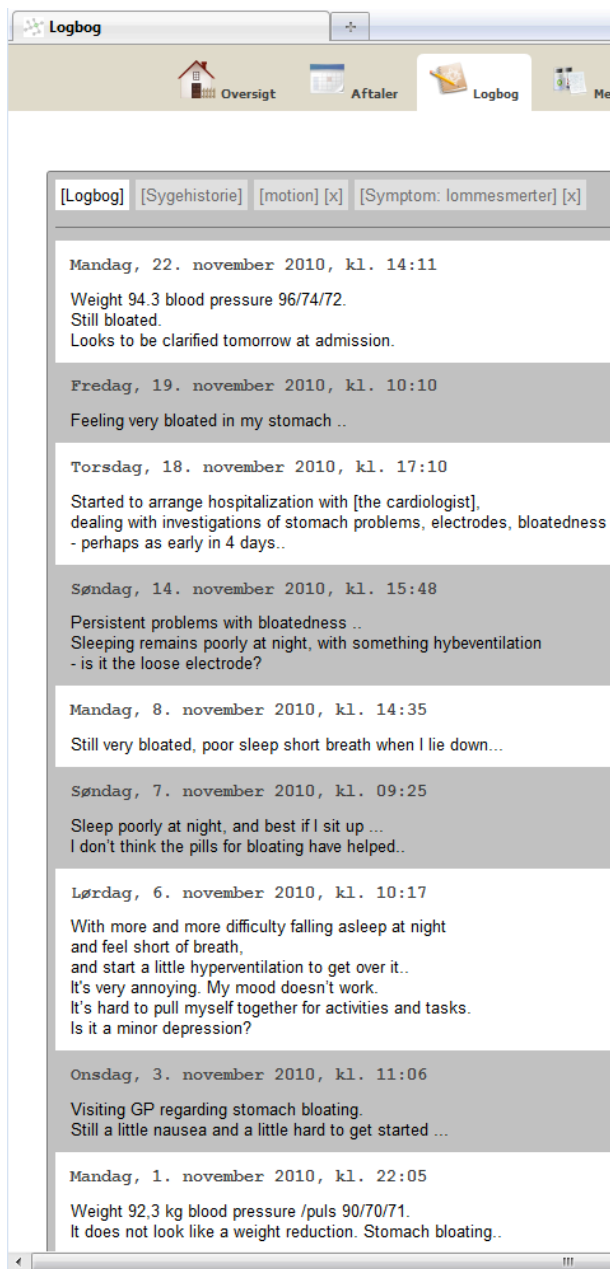
The cardiologist immediately says: "*Oh – Yes, okay [...] Karl, we've talked about that you need to find out how your breath is. This means that you every day have to go out on the street and walk until you need a break. Then it'll say [in myRecord]; Monday 50 m., Tuesday 50 m., Wednesday 45 m., Thursday 70 m. – anything [...]*"

"*You see, it would be nice for me to have a very specific test, where you've gone out and seen how far you can walk - it need not be every day - let's say two times a week. But some tasks ... But then I want concrete answers to it that way. Walking distance, weight and blood pressure.*" (audio transcription, the Heart Centre, October 29, 2010)

Later that day, the design researcher enters the task into myRecord and almost daily, for more than three weeks, Karl writes his weight and blood pressure in the logbook (picture 3). However, he never writes about his achieved walking distance, but one time he mentions: "*My mood doesn't work. It's hard to pull myself together for activities and tasks. Is it a minor depression?*" Instead, Karl's logbook entries (picture 3) reveal that his stomach bloating increases and that he "*started to arrange hospitalization*". Despite the increased attention from health professionals, Karl was admitted to the hospital after twenty days and he immediately stopped using myRecord.

MULTIPLE BECOMINGS OF HEALTHCARE

When analysing Karl's symptom log, his writings throughout three weeks (picture 3) also mirror what the cardiologist emphasized as important diagnostic information decisive for operation. Yet another, very important, diagnostic information that Karl performs could be characterised 'non-use' (Oudshoorn and Pinch, 2003) or non-completion of the walking-distance task. As a patient his active use and enactment of homework was dependent on developments in his illness and, as the case illustrates, he could not begin the task of measuring walking-distance – apparently because of his stomach bloating and physical and psychological discomfort. As such, changes in his health condition conflicts with his ambitions of writing in his Logbook. Eventually, Karl becomes unable to carry out that part of the assignment. Also, as soon as he got re-hospitalized he stops all activities of myRecord use.



Picture 3: A screenshot of Karl's logbook entries in myRecord
[Entries are shortened and translated from Danish]

The assignment in myRecord is still there but Karl is no longer able to engage the underlying logic of performing a responsible and cooperative patient. He is hospitalized and hence, patient 'non-work' or 'non-use' might be considered essential categories and made as concrete components of the socio-material conceptualization of patient homework? As of constructive insights for design, this case and other similar interventions suggest that patient homework might benefit from enabling patients to signal that they have become unable to carry out or 'hand-in' homework. Maybe homework and assignments are less fruitful notions when considering design for a socio-material reconfiguration of healthcare? Perhaps the concept of 'patient work' (Strauss and Fagerhaugh, 1997) does a better job when engaged in myRecord – and consequently enactments of another healthcare and different practices?

DISCUSSION

One of the questions treated in this paper and particular to this discussion is *how one can study something that does not yet fully exist without relying entirely on speculation*, but retaining an open ethnographic curiosity towards what is evolving as important in the field under study. A basic challenge in much design research is how to move from a primarily documentary mode of descriptive knowledge generation to sketches and enactments of possible attractive future alternatives. Instead of focusing on this movement as a transfer or translation from one kind of documentary knowledge to a different kind of speculative knowledge, we draw on approaches from design research that seek to deconstruct this principal distinction: *"The central problem is that the challenge [...] is articulated as a gulf to be bridged between observations and interventions."* (Halse, 2008). Halse argues that this often articulated 'gulf' is an outcome, rather than a premise for design. Our empirical cases from healthcare fit this argument well, in the sense that they too work to destabilize some of the conventionally opposing categories of understanding and intervening.

The design interventions point to an ongoing controversy regarding the role of the experiment in design-oriented IT research. The case examples do not live up to the paradigm of purely empirical observational ethnographic research outlined for example by Hammersley and Atkinson (2007) or as practised within ethnomethodologically informed workplace studies (Luff et al., 2000; Crabtree et al., 2009). Nor do the examples live up to purely empirical experimental research where fixed and isolated variables are sought to ensure that the experiment can be reproduced with reasonably similar results. Instead the examples reveal the unsettled status of the experiment and show how the interventional assemblages enact quick shifts in the mode of inquiry: from suggesting and promoting myRecord as a relevant solution to a practical problem, to raising new questions about the socio-material complexities of healthcare.

The assemblage instantiates new practices that incorporate diverse agendas, without trying to purify categories of 'design' or 'research'. The notion of design intervention as we treat it here is meant to challenge a commonly held simplistic dichotomy between 'the existing' and 'the possible'. The intended goal of this project is as much to understand how cardiac health care may *become something else* by means of IT as it is to create an accurate account of how it really is, when new technologies are introduced. The setup in these examples is far from stabilized and the issues under inquiry are changing during the intervention itself: from testing the relevance to practice and usability of a particular design feature to exploring what might be gained from enacting a theoretical concept such as 'patient manageability' and 'homework'. The status of the prototype can change during the intervention itself, because it is so explicitly entangled in the unpredictable interventional

assemblage of e.g. patients (who may reject to use it), clinicians (who may feel challenged) and design researchers (who report to several distinct research communities); sometimes it seems as if the research questions serve the purpose of building a better prototype while at other times the prototype appears as a mere occasion for scrutinizing healthcare.

A terminological challenge to research-through-design is that it could imply that design is a passage, whereas research is what passes through to the other side. We do not wish to invoke this particular meaning according to which means and ends appear as pre-given distinctions. While it is not only very difficult to dissect the event and claim strong distinctions between 'existing practice' and 'projected future practice', or between 'observation' and 'experimentation' in the case examples, we find it more fruitful to avoid these dichotomies all together. The seemingly oppositional characters of *describing what is* and *intervening with new proposals* may appear commonsensical, but often become obstacles for integrating research and design efforts. (Sanders in Halse et al., 2010, p.116-120). Instead, the idea of time as emergent and open, (Pickering, 1995; Law and Hassard, 1999; Barad, 2003; Latour, 2004; Whitehead, 1979) allows us to expand the implications of *the present* as a moment of unsettled opportunities, a process of creative becoming.

Our claim is that myRecord as a prototype cannot be reduced to a methodological step towards discursive insights and conversely that our research insights about cardiac health care cannot be evaluated without close reference to the embodied encounters with this particular working prototype. Because myRecord is fundamentally inseparable from the assemblage that enabled the particular kinds of interaction recounted in the examples of this paper. There are certain difficulties involved in employing design interventions as a design research strategy for exploratory questioning of a given topic rather than exclusively to test solutions. Long-standing ideals of accounting for the world 'as it is' and 'independently of the process of inquiry' are impossible to uphold with such blurred and changing distinctions between the subject, object and method of study. Above all, the interference with the subject matter by interests embodied and promoted by the individual design researcher makes this type of design intervention very hard to explain in the conventional scientific terms of validity and generalizability.

To practice this kind of design research requires researchers who are willing and able to make quick and improvised shifts in their attitude towards the research situation, rather than rely on rigorously defined methodological frameworks or step-by-step procedures. Making a daring move to present unfinished ideas to foreign project stakeholders must go hand-in-hand with humble and curious moments of listening and observing with an open mind in order to facilitate an authentic encounter between genuine concerns and projected possibilities. To appreciate the

unsettled role of the assemblage of the design intervention, it is necessary to pay close attention to the bodily presence of the design researcher and his or her often intuition-based interferences with the parameters of the design intervention: not as contamination of the situation nor an interference with the object under observation but as an intrinsic quality of the practice-based inquiry.

CONCLUSION

With this paper we propose that the conventional approach to knowledge production within the fields of IT research in healthcare, such as PD, CSCW and IS, can be fruitfully complemented by a more interventionist approach. We suggest this as a *strategy of multiple becomings*. Furthermore, we advise that a constructivist stance towards 'being' as process will allow a reconciliation of understanding and intervention, present and future.

Through three cases of design interventions we have shown the mutual connections between design proposals and the more discursive space of 'understanding healthcare'. The argument has been based on a foundational unsettling of both the mode of inquiry (observational *and* interventionist) and the role of the prototype (a solution to be evaluated *and* a research tool to generate new questions). In this light, the intervention is a manifestation of a projected reality, where a partly imaginative prototype (yet very concretely present) meets a patient willing to project her concerns and aspirations onto the prototype, whereby the lived practice that unfolds during the event entails both enactments of the past and enactments of the future. Through the emphasis on embodied encounters, design interventions present a concrete opportunity to practice and explore possible alternative realities before they are fully realized. Rather than postponing the materialization of new opportunities until the requirements are specified, we suggest to begin by instantiating ideas and hypotheses, while they are still only vaguely defined.

The design intervention is a way to supplement well-proven methods for questioning, such as ethnographic fieldwork with enactments of more material articulations of hypotheses and questions. The design intervention is an experimental inquiry that positions itself in-between what is already there and what is emerging as a possible future. With the design intervention, the assemblage allows for the multiple becomings of healthcare.

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Practicalities of Participatory Prototyping

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Practicalities of Participatory Prototyping

Designers are increasingly encouraged to develop strategies that extend the design space into the lived world of the participants. For this reason, participatory prototyping has become central to the co-design toolbox. Case studies on participatory prototyping tend to focus on the tools and techniques of making but rarely report on the mundane and background practical work required to making it possible.

Informed by science and technology studies, we turn to our own experiences and scrutinize the work that enabled us to practice participatory prototyping in healthcare. In this work we have applied design interventions as a way to extend participatory prototyping into participants' work practices. We analyse the background work and the tools that were tailored to create and maintain conditions for two prototyping interventions. This shows how participatory prototyping also gets constituted by phone calls, emails, the use of collaborative excel sheets, calendars, and word documents, as well as website and flyer production, manual system integration, and the work of setting up and negotiating appointments.

We argue that *practicalities* constitute codesign and participation and that a discourse on practicalities is paramount to improve frameworks for participatory prototyping.

Keywords: Practicalities, participatory prototyping, design interventions, prototyping, healthcare, STS, CoDesign

Introduction

Participatory design (PD) has successfully advanced methods and techniques to bridge design and use. Through the creation of prototypes and design concepts, users are actively involved to 'envision' or "simulate working in the future with the new system" ([Bødker & Grønbaek, 1991](#); [Kyng, 1995](#)). Traditionally, PD is employed to overcome the "design challenge of fully anticipating, or envisioning, use before actual use" ([Ehn, 2008, p. 92](#)). However, instead of involving participants in design and 'use-before-use'

([Redström, 2008](#)) we are increasingly encouraged to open up for use as design or design at use time ([Dittrich et al., 2002](#); [Ehn, 2008](#); [Henderson & Kyng, 1991](#); [Karasti, 2001](#)). This strategy positions design practice and the designed-for practice as collocated, rather than separated in time and space ([Hartswood et al., 2008](#)). It helps dissolve the boundary by extending the design process into the work practices of the participants.

In this paper, we subscribe to this strategy by employing recent developments of *design interventions* ([Andersen et al., 2011b](#); [Binder et al., 2011](#); [Hagen & Robertson, 2010](#); [Halse, 2008](#); [Halse et al., 2010](#)). Rooted in Blomberg et al.'s ([1995](#)) 'work-oriented design' approach that combines field studies with case-based prototyping, we integrate prototyping to become part of the actual work situations in healthcare. By design interventions we encourage participants to improvise and enact possible futures and thereby explore socio-technical change in the making.

Being successful in uniting design and use and creating a shared practice requires a great deal of work. The practical work of creating participation and continual use of working prototypes as well as all the underexposed work of setting up design interventions has been intensely present in our project. It seems that there is a whole category of hidden work, which is rarely foregrounded and explicitly discussed. By using the concept of *practicalities*, from Pedersen ([2007](#)), we want to bring forth what usually remains implicit to PD protocols and to illustrate the practical achievement it is to extend PD into the work practices of users.

Inspired by science and technology studies (STS) we employ a performative understanding of (the making of) design interventions. Instead of discussing idealized matters in abstract terms of e.g. participation and co-design, a performative understanding invites an emphasis on the *conditions* for the socio-material becoming of

design interventions, i.e. the *practical activities and tools* that goes into making it possible.

With this paper we argue that an explicit dialogue on the crucial role and importance of these practicalities is paramount if we are to improve the ways in which we carry out design interventions. By way of two empirical cases we present the necessary activities and artefacts created to maintain participation and make the design interventions possible.

Design Interventions and Participatory Prototyping

Design interventions are intentionally staged situations used to try out working prototypes and enact improvised features as part of participants' work practices. This is not an entirely new phenomenon to PD. The early studies at Xerox PARC (Blomberg et al., 1995; Suchman et al., 1998) as well as the Scandinavian approach to systems design (Greenbaum & Kyng, 1991; Grønbaek et al., 1997; Kensing, 2003) all applied various interventionist approaches to systems design.

The continued appreciation for design interventions is often accompanied by a performative understanding of PD inspired by later developments in STS (Andersen et al., 2011b; Ehn, 2008; Halse & Clark, 2008; Hertzum & Simonsen, 2010). This implies that potentials for improving work practices are seen as something that emerges as an outcome of the process – not as something that is either predicated by users or designers (Danholt, 2005). The collective engagement as a process is, nonetheless, fundamental to PD (e.g. Blomberg et al., 1995; Greenbaum & Kensing, in press; Greenbaum & Kyng, 1991; Schuler & Namioka, 1993; Suchman et al., 1998). But, as we expand below, a performative understanding of design interventions and the integration of prototypes into users' work practice foregrounds otherwise hidden activities and tools applied.

As with design interventions, prototyping is an essential part of the PD toolbox. The concept of prototyping typically covers a wide range of definitions – from early paper-based mock-ups (Ehn & Kyng, 1991) to the iterative co-design and use of working systems (Bødker & Grønbaek, 1991). Traditionally though, prototypes have been applied primarily to either explore and clarify requirements or to evaluate a proposed solution (Floyd, 1984). In this view, prototypes are used to represent the use situation, communicate design decisions and facilitate participation. Prototypes are, however, increasingly used in design interventions as means to extend the design process into the use situation. In this way, prototypes become inseparable parts of the use situation and facilitate occasions of performative design interventions. They become devices of ‘what-if’ and allow new practices to be collaboratively explored and enacted.

As described in Andersen et al. (2011b) we integrate prototypes as part of the healthcare practices through design interventions to create “situations of enactment with opportunities to live out and explore change potential.” By moving the design process into the use practice we find that practical challenges intensify. We believe it is crucial to consider these practicalities as part of reflections on the socio-material becoming of PD projects. In this article, we foreground the crucial role they play in making design interventions happen.

On Practicalities

By bringing forth the ‘hidden’ work and the tailor-made tools created to extend PD activities into participants’ work practice we illustrate the practical efforts of undertaking actual participation and co-design. The work of identifying, contacting and enrolling patients and health professionals as well as the work of staging design interventions demands continual attention and help from self-made collaborative tools. Practicalities are, as we will argue, not just *conditional* for the project, but *constitutive*

to the PD practice.

To discuss this category of work, we turn to the field of science and technology studies (STS). STS has greatly furthered the understanding of technology production to show how it is a collective and socio-material achievement, inseparable from its practice of development. By dismissing otherwise categorical dichotomies, posthuman STS analyses have helped to show how the human and non-human, the valuable and the invaluable, the high profiled (project) and the invisible are constituted by local activities and apparently mundane tools and technologies (Jensen et al. 2007). This micro-social questioning of well-known methods and techniques help to open up activities and foreground what would otherwise remain as black boxed phenomena, whose “meaning is settled so that one needs to focus only on its inputs and outputs and not on its internal complexity” (Latour 1999, p. 304).

In their influential study of laboratory work, Latour and Woolgar (1986) re-introduce attention to the ‘mere’ physical stuff (in the laboratory) through analyses of how materiality constitutes all work processes; laboratory equipment, machines, desks, graphs, documents and scientific texts. In other words, activities that involve the orchestration of a wide range of literary and material arrangements as well as banal, everyday social interaction. They illustrate, that “it is not simply that phenomena *depend* on certain material instrumentation; rather, the phenomena are *thoroughly constituted by* the material setting of the laboratory.” (1986, p. 64)

To our project, this socio-material attention invites us to open up well-established phenomena such as ‘participation’ and ‘co-design’ to be understood as being made up of many tools, various activities, and not least *practical work*. The design intervention, then, becomes inseparable from the activities and equipment that went into making it possible. Design interventions are, thus, a consequence of these activities and

exist only as networked relations in action. Put differently, the design intervention can only be understood as *performed* in, by, and through those relations (Law 2004). This marks a shift in orientation which re-installs material agency and repositions tools and activities as co-agents in performative acts, rather than passive backgrounded elements.

This approach makes it interesting to centre the attention on some of the black boxes in PD and look closely into the many times hidden work required to undertake a PD process that extends into work practices.

Opening the Black Boxes of PD

Detailed accounts on PD projects that foreground practicalities in these ways are limited, but discussions that resemble the same goals are beginning to appear. Martin et al. (2009) investigate the everyday activities of achieving participation on a large scale implementation of an electronic patient record. They found that in order for the formal plan to work, a long range of “workarounds”, “contingency plans”, and attempts to keep the project “up-to-speed” were needed. The project leader’s main activities developed into being the coordination of tasks and responsibilities, the day-to-day negotiations of conflicts and the difficulty in achieving desired participation on the project. This involved formal meetings, contracts, schedules, visits, but also informal conversations, emails, and telephone calls. Hartswood et al. (2008) propose the figure of the “IT facilitator” to engage in collaborative design as part of users’ everyday practices by helping to solve aspects of using the system, seek clarifications, inform about new features, etc. The facilitator should be able to respond to “the practical exigencies of living with the system [and] capitalize on the mundane.” (p. 86)

Bansler and Havn (2010) analyse a pilot implementation process in healthcare and identify three major difficulties that complicated the project and led to its failure. Two of the points accentuate what we would call practicalities; “Coping with unanticipated

technical and practical problems” (insufficient number of PCs in the hospital, impractical locations, sidestepping and making printouts and many “trivial problems”) and “ensuring commitment from users and their managers” (feeling of not being taken seriously, dissatisfaction, frustration and disappointment). Simonsen (2009) reports on his own experiences of being engaged in PD projects and emphasises two critical challenges for conducting action research. First of all, it is a time-consuming way of creating empirical data and risky as projects rarely evolve as planned. Secondly, it is “personally demanding and challenging”. Action research requires that the researcher “[...] has a flair and competence for project management” (ibid., p. 118). By definition, engagement and responsibility with personal stakes are a condition for being part of such projects: “I had to do something to keep the things running” (ibid., p. 120).

While some of these accounts benefit from their ethnomethodological heritage in taking serious the minutiae and seemingly mundane practicalities of extending collaborative design activities into the use practice, Pedersen (2007) goes a step further in his discussion of PD research. By analysis of the practical becoming of a PD project in manufacturing, he argues not to take the “project as a given, as simply already there, but as a *condition* for doing research that needs to be established” (2007, p. 132). By scrutinizing the principled protocols of PD, he illustrates the important formative practicalities of doing design research and directs attention to the circumstances not typically accounted for in research projects – e.g. explicating the constitutive factors for setting up participatory design activities. Pedersen (2007) shows how insights are only made ‘observable-reportable’ by way of various materials, such as documents, meetings, summaries, images, booklets, deliverables, design artefacts, the project charter, schedules and more, as well as the immense work that goes into the enrolment of participants; arranging meetings, the many email correspondences and phone calls.

This shifts the attention towards the *invisible work* and the hidden *artefacts* (Star & Strauss 1999) that go into the socio-material enactment of design interventions. In the words of Bowker and Star, it involves “foregrounding the truly backstage elements of work practice” and taking a closer look at the “boring things” of PD (Bowker & Star 2000).

[Project Name]

For nearly three years (2008-2011) we have been engaged in the design and use of two web-based prototypes in healthcare. The work presented here is part of the research and development project *[project name]*, where we engaged health professionals and heart patients with an implanted ICD (advanced pacemaker) in the Copenhagen region in Denmark. Here, care of patients with an ICD is distributed according to medical specialty. This means that the Heart Centre at the Copenhagen University Hospital is responsible for ICD-related care such as implantation and continual telemonitoring of ICD-devices, whereas the local hospitals are responsible for the medical care.

The network of health professionals who monitor and deliver healthcare is therefore inter-institutionally distributed with patients spending most of their time away from the hospitals. This disconnection of time and place challenges communication and makes organising participatory prototyping processes with design interventions even more cumbersome. From our fieldwork on telemonitoring practice, we learned that patients at home feel poorly informed about their ICD device status (e.g. battery life and registered heart arrhythmia), while bioanalysts who monitors their device transmissions lack information about the patients’ interpretation of their own condition (out of breath, abnormal heart beat, etc.). When cardiologists prepare for consultations, they lack quick access to clinical information such as patients’ health history and status. Hence, improving possibilities for sharing information between distributed patients and health

professionals became a fundamental part of the co-design and use of two collaborative prototypes:

myRecord: A patient-centric web-application that enables patients to prepare for consultations and device follow-ups, whereby bioanalysts and cardiologists are supported in decision making.

coSummary: a cardiologist-centric web-application supporting distributed cardiologists to prepare for consultations by providing a clinical summary of relevant information from the patient's trajectory.

Next, we present two case stories of how we employed design interventions with *myRecord* and *coSummary* to explore the potential for change. The cases exemplify how the prototypes are being co-designed to support patients and health professionals prepare for improved interaction. However, instead of emphasising the empirical insights (for this see [author(s) ref]) we deliberately downplay them to foreground what it takes in practical terms to set up and organize design interventions, in an effort to signify the hidden, but important, role of practicalities in PD.

Creating Conditions for Design Interventions

Prior to any design intervention, it is necessary to have identified, contacted and enrolled both patients and relevant health professionals. The success of establishing access and managing the conditions for participation (i.e. creating interest and commitment) becomes the *sine qua non* for undertaking a prototyping process with active users. This first set of practical tasks turned out to be more challenging than initially expected. Ideally we wanted a minimum of 25 patients to engage a realistic situation of use. But we quickly realized that project criteria, i.e. patients' ability to use a computer/internet, having healthcare meetings in the near future, and living in 'bike-range' from the university, were necessary for establishing possibility for a continuous

process of design and use of myRecord. Project criteria like these then became practical concerns we had to incorporate into our process of identifying, selecting, and contacting patients.

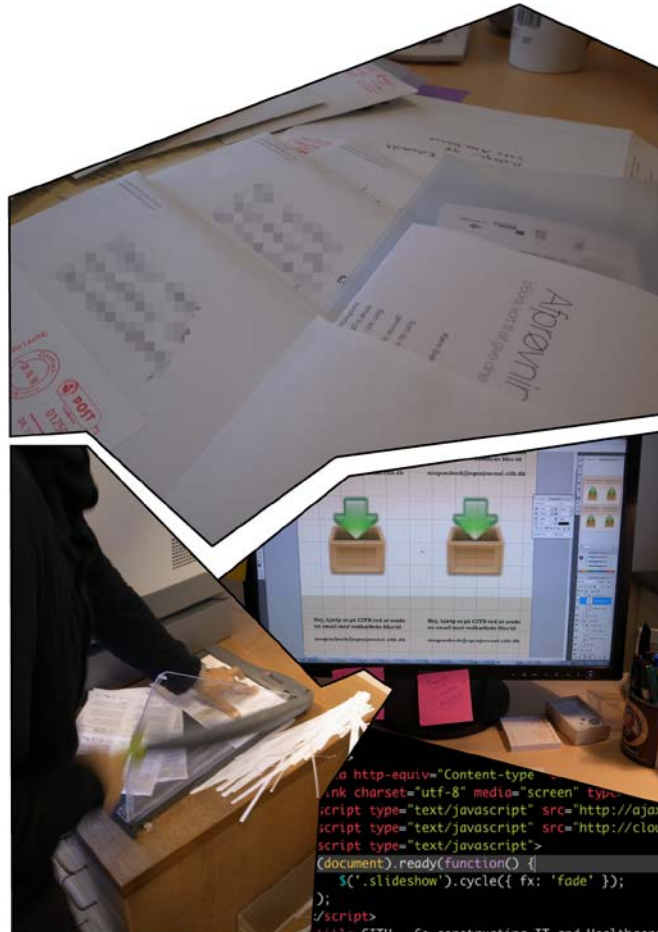
Creating the first group of participating patients took several meetings and phone conversations with health professionals at the Heart Centre and the local hospital. Generating the initial list of patients to contact was demanding as it involved setting up appointments with cardiologists, consulting various systems, applying our filter (age, sex, reason for ICD etc.) and using the health professionals' familiarity with the patients (she is no longer too ill to participate, he is friendly, talkative, might be interested). At local hospitals they do not differentiate between patients with an ICD and heart patients in general, since they are focused on medical treatment. So we arranged with the cardiologists to keep an eye out for potential patients on every consultation.

Unfortunately, these ways proved unproductive, because we were dependent on the cardiologists to *remember to* ask patients. As a consequence, we began exploring other strategies of creating interest and ways to enrol patients for participation.

Creating interest through flyers and website

One strategy was to create increased awareness about the project by enabling our call for participants to be distributed and spread across hospitals and institutions. This involved the development of a project website and A5 flyers promoting the project with the heading "Would you like to help us?" Consequently, creating the website and the flyers involved a lot of practical work that are usually left out of descriptions of PD practice. These practicalities, however, are fundamental to the becoming of a project, or in our case, actually having users of myRecord and thereby making design interventions possible. This involved to hire and collaborate with a graphical designer to create a decent layout that would provide an official and compelling look, coordinate and take

photos of researchers on the project, write informing texts about the project, set up a SkypeIn phone number with an online voicemail, get digital logos of the participating institutions, program the website, find an appropriate webhost as well as layout, print, and cut 600+ flyers.



Picture 1: [Clockwise] Mailing out flyers and invitation, creating graphic layout, programming website, cutting cardboard flyers

The website and flyers proved particularly fruitful when we combined them with a large paper-based questionnaire that was sent out to the entire pool of ICD patients (500+) in the Copenhagen region. We snail mailed a flyer (and the website URL) with each questionnaire, querying for participation on the [project name], everyday use of

computer/internet, email etc. Soon after, a couple of patients showed interest on email and we started to get messages on the voicemail. The entire responses on the questionnaire were transcribed to generate a willing-to-participate-in-[project name].xls excel spreadsheet that became a crucial tool for further selecting and contacting patients.

Managing documents and enrolling patients

We applied another strategy to ensure participation of patients who have had their ICD implant recently, because we found their information needs and activities to be quite different from experienced ICD patients who had become experts. Bringing about flyers we went to information meetings for new ICD patients and explained about the project. We also made an agreement with a secretary at the Heart Centre to filter out the referrals from local hospitals. Still, identifying heart patients who were scheduled for ICD implantation meant engaging a lot more practicalities. Before continuing, we needed clearance from the cardiologists to act as non-health professionals. We discussed the ethics of approaching patients and how to explain the project, their role and that they at any time could opt out. Then, we had to agree with the secretary what filter to apply when sampling referred patients. After a while, the secretary started to develop her own calendar-annotation to manage possible project participants and filing referrals so she could easily list patients who we could eventually contact, when we called her every Friday at 10 a.m.



Picture 2: [Clockwise] Patient preparing for consultation from home, sampling referred heart patients with secretary, project group meeting identifying and updating documents, coordinating intervention with bioanalysts

The project criteria evolved to ensure that we would have enough time to contact patients before hospitalization (min. one month). This, in turn, involved the secretary to skim the referral to check whether the patient would not be too traumatized and in a position socially and physically to take part in the project. Due to the increased complexity in the filtering criteria, we developed a new document, referred-ICD-patients.doc to collaboratively manage new patients.

The willing-to-participate-in-[project name].xls and the referred-ICD-patients.doc generated new practical tasks of further identifying, contacting and enrolling. Participation now turned from being discussed on project meetings into full weekly workshops, where we worked on selecting who to contact next (combining empirical and project criteria), what to tell them and what to remember to ask. This gave rise to new collaborative documents including another spreadsheet, sampling.xls. Sampling.xls supported the communication and coordination of who are enrolled (name, contact information, work email etc.), when and where are the next healthcare meetings, and important annotations (e.g. ‘is out travelling the first weeks of January’, ‘only using computer at work’, ‘talked to the wife who seems kind’, ‘didn’t pick up the phone’). We also created a remember-to-tell-the-patient.doc document to support what to say and ask for when emailing and calling patients.

Enrolling patients became a separate class of activities, which later started to have its own calendar time allocated (in an online project calendar) to let researchers on the project actually make calls e.g. after work hours, have time to reply on emails, listen to the SkypeIn calls as well as print, stamp, mail and manage letters of consent.

In retrospect, we would not have succeeded in conducting design interventions of myRecord and coSummary without closely pertaining to the practical work of planning, setting up and creating the conditions for participation. The many meetings, activities, the different collaborative documents, the Internet, the flyers and the project website all came to be essential in this endeavour. Having enrolled users on the project was, however, just the first step of staging the design interventions. As we illustrate in the coming two cases, it takes even more practical work to facilitate co-design as part of design and use.

Case I: Enacting Dictation Work

From the beginning of the project, patients and health professionals expressed a strong wish to improve communication among each other. Specifically, patients asked for more elaborated and personalized feedback on telemonitored device follow-ups, but due to tight schedules and limitations in IT systems, the bioanalysts at the Heart Centre worked by the principle that “*no news is good news*” and by mailing standard letters stating “*the system has been found well-functioning.*”

On these grounds, we began to co-design a new practice that would allow each patient to prepare for device follow-ups by writing specific questions and symptom experiences, while enabling Erin, the bioanalyst, to make personalized replies (for more details see Andersen et al. 2011a). Erin was a bit sceptic though, as she was worried that it would be too time consuming to address each question for every single patient.

To accommodate these wishes – i.e. to allow patients to communicate questions and comments, and enable the bioanalysts to easily deliver personalized and individual replies – we experimented with a dictation-feature in myRecord that would sidestep the current time consuming work of typing, printing, and mailing replies. As we did not have access to the hospital’s existing dictation system, nor resources to develop one from scratch, we decided to circumvent this challenge practically by using a dictating machine to integrate the functionality of making audio-replies to patients.

Staging the dictation feature

As simple as it might seem, it involved substantial amounts of practical work to set up design interventions that would allow for co-design and experimentation of the dictation feature as a seamless and fully integrated part of myRecord. First we needed to develop the feature in myRecord (sketch, find an open source audio player, write code, and test)

so that patients could annotate a limited set of questions/comments and receive audio and transcribed replies on device follow-ups. Next, we settled on a date for the design intervention with the bioanalysts and began to enrol patients. Since the design intervention was part of the bioanalysts' everyday practices of attending to all incoming transmissions we had to coordinate patients to make a device-transmission from home on the evening prior to the intervention. We wrote emails to all users of myRecord promoting the new feature, recorded and implemented 'help-videos' in myRecord describing step-by-step usage of the new feature.

We succeeded to get acceptance and commitment of using myRecord from 19 patients. To ensure that they all remembered to enter the necessary data, we phoned six patients who had not yet used myRecord on the evening prior to the transmission. Besides ensuring participation, we also learned some of the reasons that prevented patients in carrying out transmissions and using myRecord (e.g. not clicking send, "where is my password" and "I have no landline telephone and have to go to the neighbours to make the transmission").

Another practical caveat became present when faced with the security precautions typically found in healthcare organisations. Although we had developed (sketched, written code, and tested) a separate myRecord module for health professionals (with secure user management), we never succeeded to get acceptance from the IT departments to let myRecord pass firewalls and other security setups at the hospitals. In response, we started to create and bring a *myRecord pack* including paper printouts of all patients' preparations and a laptop running myRecord (with its own mobile data connection, since only patients' laptops were allowed on the hospitals wireless connection).

Intervening with the dictation feature

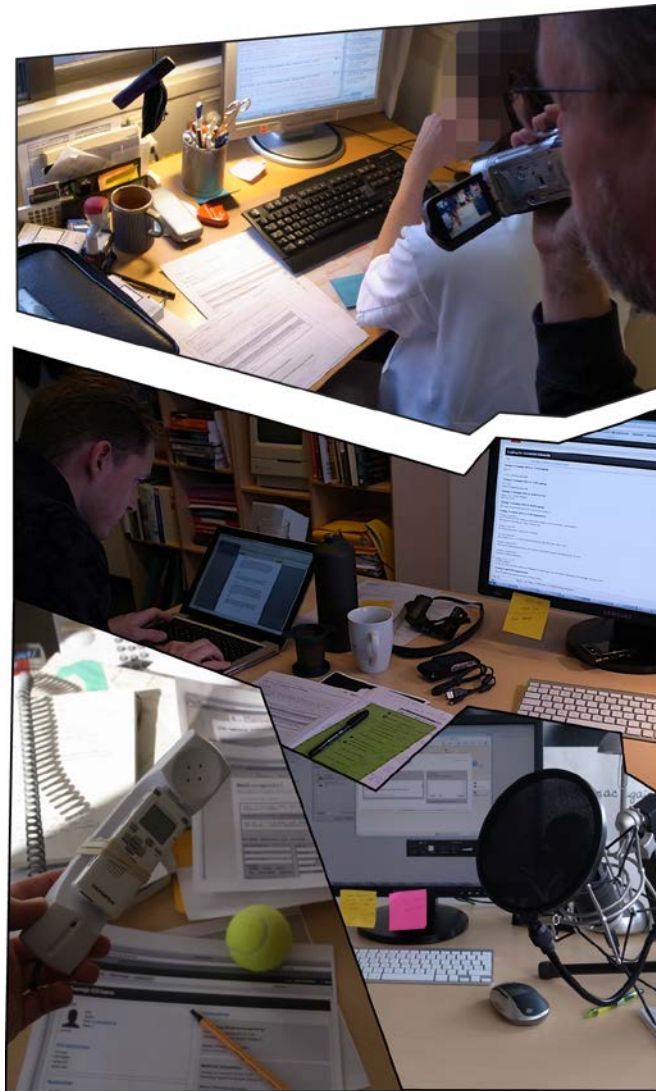
To illustrate the significance of the background work and mundane tools in constituting the design intervention, the following case shows how it enabled Erin to explore types of communication that could improve patient care. At the Heart Centre, on the day of the device-follow-ups, half way through the list of transmissions, Erin becomes alert when she correlates a patient's medication list in myRecord with an annotation of "shortness of breath". She explains: "since the patient receives medical care at another hospital, I would assume that he's already enrolled in a program at that hospital and therefore I wouldn't do any further." (audio transcription, Heart Centre, November 10, 2010)

But after talking back and forth with the design researcher discussing design opportunities for future support in situations like these, Erin decides to use her ability to dictate a message, not for the patient, but for the cardiologist at the local hospital:

"Hi, it's Erin from the Heart Centre. This is for [the local hospital] who takes care of [patient name]. Cordan was prescribed for him in August, but now he reports 'shortness of breath' and that he feels a bit dizzy [based on the patient's comments in myRecord]. But anyway, he is on Cordan and it looks like he's having increased shortness of breath. There haven't been any 'events' or anything, so Cordan has helped. Somehow though, he ought to be examined sooner than otherwise planned."

(audio transcription, Heart Centre, November 10, 2010)

In this snippet, Erin makes use of the possibility to dictate messages and suggests a cardiologist at another hospital to have a patient examined "*sooner than otherwise planned.*" Enabled by the ability to 'seamless' dictate messages to patients, Erin designs and introduces a new practice by enacting communication to actors, that we did not have in mind prior to the intervention.



Picture 3: [Clockwise] Cardiologist reviewing a case during the intervention, transcribing voice recording, making help-videos, ad-hoc recording setup

After the design intervention at the Heart Centre, the practical work of actualizing Erin's work with myRecord as an integrated part of patients' use, continued. Each audio reply had to be edited and cut (health professionals are often used to a system where they can pause and reflect while they dictate – or simply say 'delete' into the voice recorder). Next, we transcribed each reply for patients to read as text, converted, and uploaded the audio-file and the transcribed text to the corresponding patients in myRecord. The message to the cardiologist was moreover successfully delivered after

several emails to secretaries and nurses, phone calls explaining about the project for at last to get the acknowledgement that a cardiologist had received the message. A significant merit of engaging health professionals and patients as closely as we practice in interventions like these, are that they come to perform as co-designers. They are part of exploring the possible future work practice by *doing* the new practice. Their actions, feedback and critique are important parts of co-creating myRecord. As we seek to illustrate with this case, the practical work was crucial in constituting the success of this design intervention.

Case II: Enacting coSummary

In a second case we set out to explore the possibilities for assisting cardiologists in preparing for patient consultations. Patient information is currently stored in multiple information systems at different hospitals, which makes preparation a time consuming task. While the backbone of the information infrastructure is the patient record (a very large paper folder) and in particular the progress notes (short, dictated summaries of patient encounters), cardiologists also need to consider information stored in other dedicated folders or databases. In addition, cardiologists often have limited access to relevant patient information from other hospitals.

In a series of co-design workshops, cardiologists from the Heart Centre and a local hospital suggested that they only needed to share a small subset of information, and that some information produced at one hospital is often neither particularly relevant nor fully comprehensible for health professionals at other hospitals (due to a high degree of professional specialization (for more details, see Mønsted et al. 2011). In response, we collaboratively sketched the layout of coSummary, a cardiologist-centered web application that enable distributed cardiologists to share selected clinical data. coSummary is designed to explore the assumption that a summary could in fact be

composed by a collection of highly concise key indicators of a patient's clinical condition and if this would enable cardiologists at consultations to quickly gain a sufficient overview of the patient's current condition. The cardiologist however had one significant concern: coSummary could potentially add work intensive tasks to their duties. Would coSummary be so advantageous that cardiologists would continually use it?

By making coSummary part of the actual consultations, we were able to experiment with these assumptions by silently posing the question '*what do we really need to share?*' and to explore the enactment of future potential. This meant to develop a working prototype of coSummary and to stage a series of design interventions covering the full cycle from producing a summary with clinical data to using/updating the summary at consultations. We wanted to challenge the cardiologists' assumption that highly structured data could form a meaningful link between their local practices. We therefore let coSummary pose strong restrictions by validating the data that was typed in. The result was a highly structured web form consisting of 46 input fields, where the main part only allowed the cardiologists to select from five options or type in a specific year as four numbers.

Staging distributed cooperation with coSummary

Prior to the design interventions we had to identify patients with an upcoming consultation and then arrange details with the respective cardiologist and secretary. We were able to do this through myRecord, because we implemented a feature for patients to enter their healthcare appointments. While enrolment of patients was well supported by myRecord, making appointments with cardiologists proved to be cumbersome and required insisting practical work.

In this case we called the cardiologist six months prior to an intervention to carefully explain the relevance of the intervention and the possible benefits for ICD care, but as he was unaware of the project beforehand he was not particularly interested in participating. To legitimize our endeavour we had him contact – through numerous phone conversations and emails – a highly esteemed cardiologist already on our project. This only convinced him partly. The pivotal step turned out to be that the myRecord-patient was so keen on the experiment that she requested him to take part. The cardiologist gave his consent to let the design intervention occupy an extra 15 minutes.

To prepare for the consultation a summary had to be produced. These design interventions were planned to take place at cardiologists' offices. To enable them to create the summaries we had to insure that the relevant medical records were on the table, so to speak, and that access to relevant IT systems and coSummary was possible. This involved contacting secretaries to help procure the necessary documents – typically taking five days because of manual and non-automated procedures (see e.g. Nathaniel & Wall 2008). Similar to the dictation case, intervening with coSummary was met with some friction from hospitals' IT platforms and security policies. The hospitals' older desktop computers with out-dated web-browsers prevented coSummary to run, and since we did not have sufficient resources to ensure full browser compatibility, we worked around these barriers by running coSummary on our own laptops via a mobile broadband connection. This solution worked quite well and became a conventional workaround.



Picture 4: [Clockwise] coSummary (printout) in use during patient consultation, early co-design workshop, cardiologist sketching the re-designed coSummary, coSummary in use at cardiologist's office

At the consultation interventions we faced practical challenges of being constraint on time: only 15 minutes were allocated before consultations, which we used to give instructions for use of both coSummary and myRecord. For this, we developed a checklist.doc to make sure we got around the most important features of coSummary – background information on the prototype, basic instructions to the functionalities, etc.

Intervening with coSummary

To illustrate how practicalities constitute the design and use of coSummary, we turn to a situation where a cardiologist struggles to find the specific year of a patient's ICD

implantation. Sitting in his office and working on producing a summary, the cardiologist at one point needs to enter the exact year in four numbers into coSummary. He searches for the year by quickly skimming through the progress notes in the patient record and by looking up information in the hospital's cardiatric database. This gives him a broad idea about when the implantation took place, although he does not manage to locate the exact year as required by coSummary. The data he is looking for is, so to speak, drowned in the wealth of information contained in the record.

As 13 out of 46 input fields in coSummary requires a year as input, it becomes clear to the cardiologist that entering data with this level of specificity will simply be too time consuming. The actual work (use) of producing a coSummary makes him reflect on his routines. He confirms that he usually looks for this kind of information during consultations, but it is not necessary for him to know *exactly* when the patient had a device implanted, only *circa* when – as this is enough to determine how established the treatment is, which in turn implies how experienced the patient is, and so forth.

When we later raised the issue at a design workshop with cardiologists from both the Heart Centre and a local hospital they all agreed to allow more inexact data. We then collaboratively (re)designed the feature in coSummary to allow each cardiologist to mark a specific field as 'unsure' and add free text comments – e.g. an approximation of the implantation. This way, cardiologists would have to spend less time finding specific information while still being able to produce a sufficient summary for consultations.

By means of design interventions we were able to address the question of *what do we really need to share* through the actual use of coSummary. But, as we argue, what really allows the coSummary to pose the question is the collective manoeuvring of all

the background activities and tools that end up constituting the design intervention.

Without attending to all the practicalities there would not have been a coSummary at all.

Conclusions

With this paper we reflect on our experiences from uniting design and use in a participatory design project in healthcare. By foregrounding the mundane activities of staging design interventions, we show how practicalities are an essential category of work. Even though PD clearly recognize that projects are socio-materially performative, meaning that change is achieved and constituted through the collective efforts of both human actors, artefacts and design materials, we argue that the significance of practicalities in the making of design interventions are still too often undervalued and unintentionally left out of PD accounts.

Informed by the work of Pedersen (2007), we draw on insights from science studies to open up the black boxes of concepts like *co-design* and *participation*. ‘Co-design’- ready health professionals and patients are not just out-there a priori to the project. Instead, they need to be performed in, by, and through ‘invisible’ work and a myriad of helpful tools and techniques. We therefore suggest that we recognize *practicalities* as a crucial category of activities and engage a more explicit discourse on the socio-material efforts that not only conditions, but constitute design interventions.

We exemplify this by foregrounding the underexposed background work and the tailor-made tools that enable the design and use of two prototypes in healthcare. In the first case we showed how we succeeded to actualize (not just simulate) a new way to practice telemonitored follow-up of patients. During the design intervention at the Heart Centre, Erin, the bioanalysts, enacted and improvised a different way to communicate with patients. Whereby, she successfully co-designed a new feature of myRecord. In the second case, the cardiologist’s use of coSummary actualized an important re-design,

allowing another to benefit from coSummary. Through the use of the working prototype, the cardiologists enacted the new practice of distributed cooperation by sharing important information on a patient with coSummary.

Our point here is not to illustrate the favourable outcome of our design interventions, but that they would not have happened without the mobilization of a broad range of practical work and customized tools. Co-design in our examples emerged as the performative effects of a collective of tools and activities used to stage the design interventions.

In the coSummary case, medical records, hospital IT systems, coordinating health professionals and the rescheduling of consultations were all constitutive in making co-design a reality. Without the workarounds to get the prototypes running and without actively involving the esteemed cardiologist to convince her colleague to participate, the design interventions would not have actualized. It is the same story with Erin, the bioanalysts at the Heart Centre. Here, the voice recorder, the open source audio player as well our encouragement to try out the new feature is what collectively makes co-design a reality. Likewise, there would not have been any newly implanted ICD patients to enrol on the project had we not convinced the secretary to routinely call her every Friday at 10 a.m. to have her weekly list of potential candidates – in other words no sampling.doc to make enrolment a possibility.

Participation on our project is, therefore, strongly related to all these activities and overhead work typically not accounted for in PD – but probably discussed a whole lot on most projects. Participating patients and cardiologists had to be interested in becoming users, but “interest was more a verb than a noun. Interest were not a given but rather evoked, sustained and sometimes lost” (Pedersen 2007, p. 115). ‘The prototypes’ only *come into being* through the relations to health professionals, committed patients

and their use. They only ‘work’ because we, collaboratively, succeeded to actualize participation.

By the cases in this paper, we argue that the strong relationship between the mundane activities, the practicalities, and the making and constitution of the design intervention should not be disregarded. Without close attention to the background work there would not have been any interventions. Without persistent efforts to enrol and coordinate health professionals in producing and using the prototyped summaries, there would not be a coSummary in any meaningful way – only a detached prototype of a projected future. With the cases we show how the practicalities play an important role in constituting the design interventions and our argument is that practicalities cannot meaningfully be discriminated from the activities typically described in methodical accounts on design interventions. Practicalities are not a detached class of work, but an inseparable part of the socio-material collective that constitute design interventions.

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Medication Management in the Making: On Ethnography-Design Relations

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ABSTRACT

The relation between ethnography and design is often debated in terms of how to better inform or more effectively communicate insights. This prescribes a disciplinary dichotomy making the relation unnecessary troublesome. By employing an analytical framework from Science and Technology Studies and Annemarie Mol's concept of multiplicity, we investigate how the concept of "medication management" emerged on a combined CSCW and Participatory Design project in healthcare. Through this analysis, the focus is shifted from an epistemological understanding of the ethnography-design relation towards an ontological understanding, thus dissolving the disciplinary boundary. It is argued, that through design interventions with working prototypes, design and ethnography can be proactively enacted, making them interdependent and mutually constitutive.

ACM Classification Keywords

H.5.3 [Group and organizational interfaces]: Computer-supported cooperative work; J.3 Computer Applications: Life and Medical Science—Medical information systems

INTRODUCTION

In Schmidt and Bannon's [31] programmatic call for CSCW they advocate a reorientation of social science contributions to investigate exactly how insights from studies of cooperative work might be applied in the design of useful computer systems: "[T]he objective of social science contributions to CSCW should not be to cash in on the new wave and do what they have always done but rather to explore exactly how insights springing from studies of cooperative work relations might be applied and exploited in the design of useful CSCW systems". [ibid.] This paper is an ethnography about patient "medication management". It is also an ethnography about a combined CSCW and Participatory design project. But most of all, it is a reaction to the encouragement of exploring how ethnography and design may be fruitfully integrated. In this

way, it is a response to the disciplinary and philosophical problems of relating workplace studies to the design of cooperative systems.

A recurrent problem in this debate is to what extent it is beneficial to maintain the traditional divide and employ ethnography as a way to 'inform' or offer analytical 'insights' to system designers [11, 25, 28, 32]. However, working to maintain disciplinary boundaries is contradictory to the conceptual reconstruction of the sociality of technology; informational input from studies of the situation 'as is' might be outdated already when introducing the technology since it, by definition, re-configures the status quo [see e.g. 20, 34]. Related to this problem is the problem of 'representations' as opposed to a working system or a prototype. Suggestions of how to mediate the ethnography-design relation should not be a matter of effectively communicating analytical insights but moreover how to fruitfully enact practices of design and ethnography as part of a shared practice. Keeping disciplines distinct makes connecting them troublesome, which we and others argue, they should not be [9, 17].

As a way to challenge and reformulate the ethnography-design relations, we turn to our own work of integrating ethnography and design. By an investigation of how "medication management" emerged on a CSCW and Participatory Design project in healthcare we suggest a reformulation of disciplinary boundaries. This suggestion is based on a move away from an epistemological mode of undertaking ethnography-design relations towards an ontological mode.

DISCIPLINARY DICHOTOMIES (AND CONVERGENCES)

Fieldwork methods and especially ethnomethodological ethnography have since the early 1980s been foundational to CSCW research. In contrast to focusing on a better 'cognitive coupling' between the computer and the user, the turn to the social has re-formulated the challenge for design of computer systems to essentially being a matter of better understanding the social organization of activity as situated, relative to, and dependent on the situation of application [4, 10, 15]. Influential studies that have shaped the field are commonly known as 'workplace studies', which are naturalistic studies of complex cooperative environments where people are considered inseparable from the situated

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and contingent unfolding of activities in which tools and technologies are used [25]. Workplace studies are informed by diversity of approaches but a major influence comes from the post war Chicago School sociologists who adopted ethnographic methods in the application of studying locale urban life.

This socio-anthropological heritage and the employment of ethnography form the basis of two distinct concerns. One is the *crafting and reconsidering of concepts and theories* and the other, which is highly related, is the *commitment to analysis* as a component of ethnography [25, 32]. These methodological and epistemological underpinnings have been not only interdisciplinary and innovatively performative in CSCW but simultaneously the root to the problematization of the relations between ethnography and design. The issues pertaining to the ethnography-design relations are, to a large extent, a matter of an interest in preserving disciplinary boundaries.

Ethnography to Inform Design

The crafting of analytical concepts and theoretical constructs such as ‘computational coordination mechanisms’ [32] and ‘artefactual multiplicity’ [6] is a cornerstone of CSCW research. Such contributions might be coined in the interests of systems design practitioners but the principal motivations behind them are, perhaps more to the point, the long term contribution to the reshaping of the ways in which we conceive everyday social actions and interactions in the workplace [25, 32]. Schmidt [32] considers the most influential workplace studies to be those that are unbound to specific design efforts.

The conceptual and analytical genre, which workplace studies exemplify, is foundational to CSCW research. Traditionally, and to some influential people in CSCW, ethnography is not merely a technique for collection and organization of data but moreover a research process that engages a “conceptual distance” by applying theory to the reading of the empirical data [13]. This definition is shared in ethnomethodological ethnography, which rejects sociological theorizing by arguing for accounting on “what people actually do” [11]. Besides well-established methodologies for data gathering, ethnography necessarily involves a reflexive philosophical stance or as Dourish [12] puts it: “[E]thnography makes conceptual claims; it theorizes its subjects, even if the theories presented are the subjects’ own”. Keeping to such principles means engaging a distinct analytic orientation to fieldwork capable of unpacking the rationality of ‘work’ as opposed to producing shallow descriptions.

Despite this (orthodox) understanding, the term “ethnography” has for some reason become an umbrella term in CSCW and HCI, labeling a long range of fieldwork investigations used for requirements gathering. This includes Contextual Inquiry and Cultural Probes [14, 18] but also investigations with no philosophical grounding,

mainly applied to extract data from the settings under study. Approaches that recognize the disconnect with “pure” ethnographic practices have been labeled “quick-and-dirty ethnography” [30] while terms such as “scenic fieldwork” [8] or “quasi-ethnographic work” [13] points to the weaknesses of not adhering to the principles of ethnography. Similarly, Anderson [3] argues that employing ethnography in design as a data collection strategy is based on a misunderstanding. The failure to appreciate ethnography’s analytic aspirations misconstrues the character of ethnography and consistently marginalizes or subverts the analytic component of ethnography. Dourish [12] extends this argument onto the approach of “implications for design”, which has become a natural end-point to many CSCW ethnographies. Translating analytical insights to implications for design does not succeed to utilize the potential of ethnography in systems design: “... *a bullet list of design implications formulated by an ethnographer is not the most effective or appropriate method*” [ibid.]. The value of ethnography, he suggests, is in the models it provides and in the ways of approaching an organization or social setting.

When enforcing the principles of traditional ethnography the relations between ethnography and systems design are made problematic [8, 12, 30, 31]. It creates a big discrepancy between naturalistic accounts and the way such information (traditionally in literary form i.e. texts) can be of practical use to system developers. For this reason it has become part of the ethnography-design discourse to talk about the disciplinary connection as a “gap to be bridged” [28] and discussing it along dividing lines revealing disciplinary dichotomies i.e. descriptive vs. prescriptive, particular vs. general, present vs. future, understanding vs. intervention [20]. Thus, articulating the ethnography-design relation in terms of a ‘link’ and as a matter of overcoming differences installs a model of disciplinary dichotomy. The response to such a model is to develop ways of how to ‘inform’, offer ‘insights’, ‘input’, and ‘suggestions’ [28] to design, thus reproducing the disciplinary boundary: “*Our purpose is to inform systems designers – i.e., those parties who are actively involved in the development of computing systems and applications [...]*” [11]. Solutions to the methodological division of practices are to “iteratively” incorporate fieldwork analysis into “requirements capture process” [30] and secure ways of effective communication between ethnographers and designers. Again, this installs a model of a hierarchical relations where ethnography is framed as subordination-service to systems designers [5].

Ethnography and PD

However, the ethnography-design relation in CSCW has been performed in a myriad of innovative ways that in practice, disregards the disciplinary divide. But to be fair, it is only a few in CSCW that have worked explicitly methodological towards dissolving the boundaries of ethnographic and design practices [e.g. 17, 20, 34]. In

related fields the ethnography-design relations are not considered problematic in part because of influences from contemporary movements in social science [24] and design research [23] where disciplinary dichotomies are contested. Here, ethnography is considered interventionist and employed as inseparable from the object of designing innovative technologies and producing novel research contributions [see e.g. 19, 29]. In CSCW however, methodological discourses on the ethnography-design relations tend to be bound to the model of disciplinary dichotomy.

Nevertheless, methodologies are appearing that transcend the boundaries and suggest the integration of, in particular, participatory design and ethnography. PD is historically strongly associated with CSCW in part by a shared social scientific heritage and in part by a shared focus on technology design [21]. Where research in CSCW tends to have an analytical focus, PD research differs by having more practical and design oriented methodologies. In PD, the dominating discourses are on the politics of design, the nature of participation, and methods, tools and techniques for carrying out design projects [21]. Ethnography has, although, always been an important component of PD [33] and is many times explicitly integrated in principles, tools and techniques [22]. For these reasons, PD has been imported on practical premises and in later work as part of methodological alternatives of integrating ethnography and design. Below we foreground contributions that transcend the division and push for a mode of interdisciplinarity that aims to be “synthesis-integrative” [5].

Design Interventions (Reflexive Relation)

Early studies at Xerox Park have been central to the development of both the ethnographic tradition in CSCW and in PD. Suchman, Blomberg, Orr, Trigg, and others [34] have been widely influential in particular by their reflexive integration of 1) the discursive reconstruction of “technology as social practice”, 2) ethnographic studies of work and “technologies-in-use”, and 3) “design interventions” as a work-oriented and cooperative strategy for novel technology production. Through this interworking they propose a research strategy that “*establish relations with specific work settings and to use those as sites for cooperative applications design*” [34]. With a similar ambition, Karasti [20] reconceptualizes the disciplinary dichotomy between ethnography and participatory design by integrating systemic analysis and “appreciative intervention”. On the basis of shared analysis of co-viewing video collages the practitioners use analogies to propose new tools. Here, presence and change gets intertwined through collaborate evaluation and envisionment of new technology i.e. by projecting the design suggestions into their ‘lived experience’ (through dialogue) of the future practice simulating “technology-in-use”.

Co-realization (Creating Shared Practice)

Büscher, Gill, Mogensen, and Shapiro [9] propose a ‘bricolage’ approach as a way to develop the relationship between ethnographic and participatory approaches to design. By empirical examples they propose this as a way to develop CSCW ‘*in practice*’ [See also 36 for ‘in-situ appropriation’]. By empirical examples, they show how they step-by-step and through ‘situated experimentation’ and “careful attunement to the circumstances of work” cope with the uncertainty that arises when introducing new technology to work practice. They call for a co-evolution of technology and work practices through inter-connected cycles of ethnographic and conceptual analyses of the social organization of work and the participation of practitioners as co-designers. Bricolage engages design as assembly, and in practice it means “‘designing immediately’, using ready-at-hand materials and combinations of already existing pieces of technology” [ibid.].

Hartswood et al. [17] acknowledge the fundamental problem of letting ethnomethodologists act as a proxy for users i.e. making visible the detailed aspects of a workplace as an informational input and as part of requirements capturing. As they put it, the designer wants to know about what implications the insights might have for design and use of new systems whereas the ethnomethodologist “will insist, that such questions can only be answered in, and through, use of the new system” [ibid.]. They turn to PD for innovative socio-technical ways of tackling the user-designer relations. However, there are, as they argue, also shortcomings of PD approaches. This includes the limitations of representations and scenarios (they are different from the system itself) and that few PD projects move beyond the design phase into implementation. Hartswood et al. suggest overcoming these troublesome user-designer relations by creating a *shared practice* between users and IT professionals that is grounded in the lived experiences of users. *Co-realization*, they call it.

ANALYTICAL FRAMEWORK: STS

Now, turning to our own work we present an approach where the boundary between ethnographic practice and participatory design practice converges. In many ways our approach resembles the methods presented above where a reflexive relationship between studying and designing technologies-in-use, in-situ appropriation and co-realization of design and use, is undertaken. However, in other ways we present a more radical integration and synthesis of ethnography and design. We want to suggest a shift in thinking and practicing ethnography-design relations as an orientation towards “effecting ontological change” [5]. By this we mean to give up on the disciplinary dichotomy and to begin making ethnography and design mutually constitutive in methodological enactments. To enable an investigation of the ways in which ethnography and design are synthesized and methodologically converged, we need an analytical framework capable of foregrounding the

minute transformations in the relations between multiple practices.

To leverage this, we make a philosophical gear-shift and look to science and technology studies (STS) where a (similar) move from an epistemological mode towards an ontological mode of unpacking socio-material practices is emphasized. In her book, 'the Body Multiple: ontology in medical practice', Mol [26] makes the argument that the illness of atherosclerosis is not singular, but multiple. With this somehow paradoxical argument, she engages an ontological shift by empirically foregrounding how atherosclerosis *exists* only in relation to practices. This stands in contrast to the modernist and normative understanding of an illness since atherosclerosis, then, can only be understood as relative to a situation. It is no longer meaningful to speak of atherosclerosis without speaking of the socio-material practices that performs it. 'Atherosclerosis' is therefore not something universal and singular, as in medical scientific accounts, but multiple and enacted in different ways across various sites, with different bodies, and with various tools and technologies. It makes sense only to understand the illness as of 'when' and not as of 'what'. Again, this is an ontological move since Mol is no longer interested in acquiring knowledge in an epistemological way, as a matter of creating true references but moreover she is concerned with knowledge as a matter of "manipulation": *"The driving question is no longer "how to find the truth?" but "how are objects [or phenomena such as atherosclerosis and medication management] handled in practice?"*.

According to Mol, there are *multiple* atherosclerosis i.e. each site produces its own version of atherosclerosis. The multiplicity of reality has methodological implications. Fundamentally it makes a shift from believing that methods discover and depict realities to, instead, argue that methods participate in the enactment of those realities [24]. This is grounding Law's [ibid.] project of arguing that methods and their rules and practices *"not only describe but help to produce the reality that they understand"*. *The intuition becomes that "scientific knowledge and technologies do not evolve in a vacuum. Rather they participate in the social world, being shaped by *it*, and simultaneously *shaping it*."* [ibid.] In practice *"science *produces* its realities as well as describing them"*. Mol and Law's work signify a shift from investigating the "doing", "being", "how phenomena becomes", or importantly, "how phenomena is enacted?". To the project of this paper and to the question of understanding the emergence of 'medication management' and its relations to ethnography and design, it then becomes a question of *"how is medication management enacted, where and with what tools by what practices?"*

In the following we investigate exactly this; how the concept of 'medication management' has been enacted throughout the [project name] project; at different sites in different practices with different prototypes and artifacts

and at different points in time. By investigating how it emerges *relationally* between practices of design and research, patients and clinicians, it is made possible to understand what *modes* and *logics* of interdisciplinarity are performed. As a way to illustrate how methods on the project have become disciplinary converged we analyze how ethnography and participatory design methods have been entangled in the co-construction of medication management. The analysis is divided into three figurative stages to look more closely at the transformation of methods and techniques from traditionally different disciplines. The stages of enactment are thus (1) Ethnographic, (2) Participatory design, and (3) Disciplinary convergence.

"MEDICATION MANAGEMENT" IN THE MAKING

[Project name] is a research and development project of collaborative practices among heterogeneous actors involved in health care for heart failure patients with an ICD (advanced pacemaker) in the Copenhagen Region, Denmark. The first period of the project, 2008-2011, has contracted an interdisciplinary project group consisting of 11 researchers with backgrounds in Cardiology, Health Informatics, Computer Science, Information Technology, and Sociology. The sub-project we are reporting from here has over the course of the project involved more than 30 patients and their relatives as well as a heterogeneous group of health professionals; 4 nurses, 4 bioanalysts, 5 Secretaries, and 7 cardiologists. The care for ICD patients is distributed according to specialty; medical care is carried out at local hospitals whereas ICD device-centered care is carried out at the Heart Centre at the Copenhagen University Hospital.

Ethnographic Enactments

The first activities on the project were ethnographic. This involved fieldwork; in situ observations and interviews at the participating hospitals and in patients' homes but also various project meetings, seminars and activities of defining, communicating and anchoring the project (i.e. creating and distributing A5 flyers, a project website, a conference poster etc.). Focus was on getting the project in motion, access to field sites, and creating a shared understanding of the distributed treatment organization and practices of heart patients with an ICD. By ethnographic fieldwork we established insights that proved to be vital for the development of the web-based prototype of a personal health record. In the business of ethnography, a relatively mundane tool that became useful for project collaboration when preparing for and conducting field visits was the patient interview guide. Alongside the interview guide followed a tape recorder, a notebook, and a camera. An early version of the patient interview guide an interest in patients' management of medication becomes visible: *"How is medication managed? Which medicine? What are your experiences from taking the medicine?"*

Through initial field trips to patient homes, we quickly found that the management of medication is innate part of ICD patients' everyday practices. Consider a snippet from the very first ethnographic field trip to Hans' home (an invented name of a participating patient. All names in quotes and stories are anonymized).

Well into the interview, the Design researcher asks Hans: "Is there any medication you take every day? Hans: Oh, yes. I have to take 14 pills a day. Something called Dimitone [heart medicine; beta blocker], I have to raise the dosage every day – right. I need to reach 25 mg twice a day, but I have a hard time doing it, because I get so dizzy, right." Design researcher: "How do you get a hold of the medicine and how does that work - you get a prescription?" Hans: "Then I call my own doctor and he rings the pharmacy, right." Design researcher: "And then you go to the pharmacy?" Hans: Oh no, then my friend fetches it. Or.. yes, sometimes I take the bus down there. Completely helpless, I'm not yet."

From this interview and others, we learned that the majority of the patients take a variety of pills at different times every day. The individual act of pouring up a glass of water and swallow the pills is just a minor part of it. The work of keeping track of pills running out and getting the medication home is a collaborative activity. Hans needs to contact his GP to prescribe the medicine and sometimes relatives or friends help by going to the pharmacy in opening hours and bringing the medicine to his home. Medicine management is also about keeping track of dosage. As with Hans, experienced symptoms and side effects have crucial consequences for everyday life such as dealing with side effect of dizziness and being tired. They become fundamental to the practice of medication management: "Can I cope with taking more milligrams Dimitone today? Maybe I should not experiment tomorrow when I leave the house to go shopping". Moreover, such experiences are not only relevant for Hans' and other patients' practices of medication management at home. Experiences become essential information in the cooperation with cardiologists in medical treatment. This is made present in the following snap shot from an early observation of medical treatment – a cardiologist-patient consultation, in a regional hospital of Copenhagen.

Not long into the conversation, Kurt says: I'm a bit more worried about my diet situation - I've lost five kilos in 2-2 ½ months. I was so proud when I reached 70 kilos, now I'm down to 65. It's obvious, because the food runs straight through me. The cardiologist says: Hmm.... do you have an idea, which of the pills we've given you makes the problem? Kurt and the cardiologist discuss back and forth about Kurt's experiences and settle on a drug called Selo-Zok. Then they discuss whether or not he should stick to the high dose. Kurt explains that after the increase in dose he is able to walk to the third floor without any problems. But now he

has trouble with his stomach. Nonetheless, the cardiologist insists that he sticks to the high dosage.

From this snippet we see that Kurt has correlated the increase in dose of Selo-Zok with improvements in his physical condition. Living on the third floor is no longer a problem because he feels the symptoms of shortness of breath are disappearing. This is crucial information for the cardiologist since it reaffirms that the medicine is working. However, Kurt expresses his concern about the possible side effects; poor appetite and diarrhea. He indicates that he has kept track of his weight and that he lost five kg. This information, as well as Kurt's request of a prescription makes the cardiologist write, stamp and sign a prescription for a different but related drug with supposedly fewer side effects. Fundamental to Kurt's successful medication management is therefore to monitor, and importantly, share why, when and where symptoms and side effects are experienced. Medication management is inherently cooperative and involves good memory that is many times supported by conversations with relatives and the writing down (on paper) symptoms, side effects, and questions. Successful medication management, then, is also about successful information management.

At this stage, Hans' and Kurt's 'medication management' is left relatively untouched. The interviews and observations have had very little, maybe even no effect, on the way they manage medication. Perhaps, they would not even think of all the activities and people involved in the work of managing medication as "medication management" but more or less in their own terms and as a routine part of what it means to them being a chronic ill patient. Hans and Kurt probably continue relying on their memory or on their paper notes when seeing the doctor and getting new prescriptions. The patients' practices of managing medication are so far left untouched by us as design researchers and the project as a whole.

However, the field visits had affected our (the design researchers') work on the project. We began discussing observations and thoughts with fellow colleagues and listened to the audio recordings and made transcriptions of them. A range of documents such as transcriptions from field visits and working papers were created to support a shared understanding. Also a collaborative document called 'Design concepts' was created to capture ideas for design solutions and formulate implications for design. Revisiting some of these documents reveals that the interest in the patients' work on medication management continues to travel. Moreover, the shareable document, 'Design Concepts' (also mostly in use the beginning of the project) holds a description of the initial ideas for solutions to problems found. One design concept (out 13) says is about; "Dialogue Support – qualifying the dialogue between patient and health professional [...] This design theme addresses some of the challenges that exist in the treatment-dialogue between patients and health professionals [...]" In

the section “Problems and Consequences” it says: “As a basis for consultations with patients, Health professionals are uninformed. The cardiologist spends a considerable amount of time asking the patient about experienced conditions around medication and health status – in the period since their last meeting.”

In terms of the genre of “implications for design” it would at this point be fair to say that the objective is accomplished. Fieldwork has been carried out, observations and interviews conducted, naturalistic descriptions have been created and implications for design have been formulated using a range of collaborative documents and tools normally found in a fieldworker’s toolbox. It should be noted, that what we have just presented is a compressed version of what we mean by ethnography informing design and it is framed to exemplify how ethnographic work (tape recorders, interview guides, working papers etc.) have enacted “medication management” so far. It reproduces an epistemological mode of performing the connection between ethnography and design by, to a large extent, keeping patients and health professionals and design researchers’ practices apart. The product of research is mostly materialized as text in digital documents and performed at separate sites. It has more or less reproduced a hierarchical model of interdisciplinarity making ethnography a “subordination-service” to design [5] i.e. providing access and insights that other methods would not be able to provide.

Participatory Design Enactments

With the same design interventionist intentions as Suchman et al. [34], Karasti [20], Büscher et al. [9], and Hartwood et al. [17] we turned to Participatory Design and cooperative prototyping to look for methods, tools and techniques that could make the project more change oriented. Practices that would help enact the findings (e.g. new forms of medication management) from the fieldwork. We wanted to challenge conventional ethnographic methods to become even more interventionist by rethinking the ways in which ethnography is undertaken. We were looking to create a form of ‘shared practice’ with the participants and to incorporate a critically analytical sensibility. Essentially, we wanted to not only think, write and discuss “medication management” and design implications, but to simultaneously actualize a potentially new form of medication management as part of the participants’ practices. As we shall see, the project therefore came to include co-design workshops, web-page sketching and cooperative prototyping of a patient-centered web-application and we began to put more effort in promoting the project (i.e. making graphically inspiring invitations to workshops and making sure participants felt empowered through participating in the project).

To begin a transition towards actualizing design in-situ or as part of a use situation we carried out what we called a situation-card workshop. We arranged a workshop to co-

explore and validate insights from the ethnographic activities and to enable co-design of solutions to experienced problems. Inspired by design games, we developed a game board and twenty ‘situation cards’ divided into four themes (e.g. ‘Medication’, ‘Capturing Experiences’) with an introductory text and a selection of related questions. Consider the following snippet, where the four participating patients; Preben, Povl, Niels, and Flemming [anonymized] discuss practices related to medication management.

About half an hour into the workshop, Preben picks up a card and reads it aloud: “You have arrived at the cardiac department at the local hospital and the doctor calls you in.” Preben begins talking and tells about a visit to his GP. Then a design researcher says: “You also have the challenge, remembering whether there have been adjustments to the medication...” Preben: “Well, I don’t think it’s a problem. I think I get 25 pills a day and I can name exactly what they are called, how much and how strong they are, how many mg they are and so on. It’s not yet a problem for me”. Povl says: “I get 3 pills a day” and Niels interrupts by taking out a little homemade laminated plastic card with a medicine list, from his wallet: “But you’re all so young, I only get 6 ... 7 pills a day. I always bring this one with me [shows a handmade medicine-card with a list of his medicine]; what is the medicine for, what kind of medicine is it... because I’m sorry, I can’t remember their names and the dosage. Preben admits that it is a good idea and that he actually has one on his computer at home. Povl says: “I just think it’s hard to remember these things, because one day the name is this and the next day...” The others agree: “Yes exactly and I agree”. Flemming continues: “I’d just like to say, I only get two kinds, and now I can’t remember what they are called, because - hahaha, I know the original is Odrik and Dimetone, right.” Again everyone is agreeing. “They give us the generic drugs, which is the same but cheaper for us, right” (Transcription from audio recording, May, 2009)

In the snippet above, it becomes clear that the patients have medicine prescribed from various institutions and that it is the prescribing institution’s responsibility to follow up on the specific drug. The format also provided for discussions of the idea of having one’s own medicine list written down for example on the computer or as a note in the wallet. In the end they hint that this could potentially be a tool that could support them because the names of the (same) drugs often change. Now, medication management is enacted at the university with a cardboard game prompting discussions and sharing different ways of keeping track of medicine. In the workshops, the interview guide has materialized into a cardboard game and is no longer asking about previous experiences but probing into how patients would manage a list of medication in the future.

As part of the interventionist ambitions we decided that we needed to begin prototyping if ever to get answers on the

real value of the ideas that were emerging. We took on an iterative development approach and made the first prototype become a mix of being a design research probe and a tool for patients by resembling an online diary. It embodied questions such as “what symptom experiences and medical side effects would you [the patient] write about if your doctor could see it?” and “how might this tool [prototype of personal health record] support collaborative healthcare and enable patients to actively participate?”. The first prototype was therefore relatively weak in terms of what functionality it stipulated, leaving room for patients own interpretation. Within four months we employed a web developer, sketched, implemented and held two launch workshops where we provided twelve patients with login to their own profile in the prototype.

The twelve patients who were signed up for using the first version of the prototype, wrote various things including experienced symptoms, questions in relation to their ICD, summaries of consultations, and other diary entries. The majority wrote about their medication and one patient entered his own complete version of a medicine list. The list reveals how he enacts medication management by explicating at what time, how many pills should be taken (morning, evening), their intended effect (e.g. diuretic, rhythm stabilizing, anticoagulant), how many milligrams, and the name of the generic drug name (e.g. Cordan):

“Morning Evening For:

Selo-Zok (metopulosuccinat) 1A Pharma 50mg 1 rhythm-stabilizing

Spiron 25mg 1 diuretic

Trandolapril 0.5 mg 2 strengthens the heart

Aspirin 75mg 1 against thrombosis

Furix 40mg 1 diuretic

Kaleorid 1 750mg potassium supplements

Cordarone (Cordan) 200mg 1 rhythm-stabilizing

Simvastatin 40mg 1 cholesterol-lowering

Marevan 2.5 mg Agreement anticoagulant”* (Transcription from the prototype v. 1.0, translated from Danish)

As a way to qualify what the participating patients had written, we arranged for co-design sessions in patients’ homes. In this way, we could combine elicitation studies (discussing patient generated empirical data) with co-designing features of the second version of the prototype. The result of these co-design sessions was a collective decision to include a “Medication Profile” in the next version of the prototype. To aid sketching the “Medication Profile” web-page (and 2 other web-pages) we arranged for another co-design workshop with patients at the university and several co-design workshops with cardiologists and bioanalysts from the participating hospitals. After debriefing sessions, mini-workshops, co-sketching of web-page features – the web-developer would take time to sit, either at home or in his office on the fifth floor at the university, to program the second version of the web-based prototype. Soon after, the second version of the prototype

was launched in collaboration with 23 participating patients, now with the possibility to communicate with clinicians (a module for clinicians).

At this stage, the project has moved from a focus on creating an understanding of “medication management” (among other concepts) towards the participatory design of “medication management”. A shift in research mode has engaged a range of other activities including co-design workshops at the university, co-design sessions in patients’ homes, co-sketching, development of two prototypes and patients using the prototype from home. These types of activities are all central to the Participatory Design methods-tools-and-techniques catalogue and are in this respect not very exotic. But, in an STS-framing where activities and tools are foregrounded, it becomes visible how the ethnographic practices and the practices of design have started to converge.

Interdisciplinary Enactments

The second version of the prototype included features that made it possible to trial it as a collaborative tool and as an integrated part of health care. In this way, the ethnographic studies of the prototype-in-use changed radically because the boundaries between use, design, and ethnographic inquiry were severely blurred. It was no longer fruitful to characterize method activities as belonging to one or the other discipline. *Design interventions*, for example, became moments where multiple practices were enacted simultaneously [2]. Situations of trialing the prototype as e.g. part of a medical consultation, was not just moments where we could apply our ethnographic curiosity and study use i.e. the (new) ways in which medication management with the prototype unfolded. It was moreover situations where we could intervene and cooperatively re-design or suggest new features etc.

By critically analyzing the design interventions with the working prototype we realized that we had introduced a new category of (invisible) patient work [1]. With the prototype installed in use, “medication management” is expanded, introducing expectations of active patient participation. Patients now need to log in to the prototype from home and write about their experienced symptoms, side effects and medicine list. They are asked to approve the medication profile they have entered as a way to communicate to clinicians that this is their updated list. The integration of an analytical dimension (ethnographic reflexivity) in design interventions led to the discovery of new ways of relating ethnography and design. The prototype had become useful, not only to perform a newly designed and possibly better way of managing medication, but it had also become an “inquiry device” capable of providing answers to critical questions. This meant that developing prototype features and trying them out could be applied as a different, critical way of studying, while designing, for emergent forms of medication management. When installing the prototype in practice it was made

possible to probe into new ways of combining collaborative technologies (the prototype) and active patient participation. In other words, enabling patients to remotely collaborate with clinicians around their medication was at once another way of performing literary categories [see e.g. 2] such as 'Patient 2.0' [7] and 'diagnostic agency' [27]. While these concepts are coined on the basis of *retrospective analysis*, the embodiment of the prototype in the healthcare network and in design interventions provides ways for *prospective analysis* [35]. Therefore, analytical reflexivity (ethnography) could be mixed with participatory design when undertaking design interventions. For example, the re-configuration of medication management (i.e. the network of patients, clinicians, and the prototype) necessarily meant that patients had to do more 'invisible work' [27] or 'homework' [16], which accentuates implications of increased patient responsibility. This analytical extension of 'medication management' could become otherwise than an analytical insight. It could be enacted through design interventions and thus take active part in the patients and clinicians practices as well as in the ethnography-design practices. Oudshoorn's notion of diagnostic agency and 'homework' (see [37] for similar use in CSCW), could be installed in situations of use by developing features that would potentially become part of patients and clinicians use of the prototype.

To experiment with proactive analysis, we sketched and implemented a feature in the prototype called 'Assignments' to make it possible to inquire into the relation between managing medication and doing 'homework' with the prototype. In the following snippet, a third version of the prototype has been launched and a patient, Karl, has agreed to prepare for an upcoming medical consultation. He uses the prototype to communicate his medication profile, symptom experiences, and side effects and in turn, the cardiologist uses the prototype and Karl's writing as support for his own preparation. However, neither the cardiologist nor the patient have been introduced to the new feature 'Assignment' prior to the design intervention.

The design researcher arrives at the outpatient clinic with the patient and his wife and agrees with the cardiologist to follow him to his office to collect various documents and prepare for the medical consultation. It is the first time they meet so the design researcher hands over a printed version of Karl's preparation and explains in very short terms what the project is about and reads the first couple of lines from Karl's summary (5 lines in total). The cardiologist mumbles and reads through the rest of the notes and Karl's medication profile. Then, he collects various documents and test results and a while after they walk over to pick up Karl and his wife to start the consultation. The cardiologist says: "You have completed this [printout from the prototype], and it was actually very helpful because you've explained very well what we really need to talk about ... precisely as you have written three weeks have past and we

must find out - from how you feel, what the plan should be". Karl replies: "I've been really ill... air ... and sadness. I've not being able to pull themselves together".

They talk through the various symptoms and questions from the prototype print-out and at one point the wife interferes: "But Karl, if I may say something, it's also been worse now that your belly is bigger". Karl says: "Well, see it's a bit complicated. Now, down here [looking down and pointing to his stomach], I was usually fit and I could see my penis and all the funny parts but dammit, now I can't any more. It means that I have either air or water in the stomach". The cardiologist agrees. Karl continues: "Look, something like that also affects the air in the stomach [pointing at the prototype medication profile]?" They are both sitting bend over, looking at the printout. The cardiologist: "Yes it does. You puff more, your appetite gets poorer and so on and so on - if you've got water in the stomach. And the things you've mentioned here... [pointing at the prototype print-out]... I think what we do is: We wait and see a couple of weeks: You have to exercise and use your body, we increase the diuretic medicine [Furix] because it forces the water out of the stomach ...". They continue the discussion back and forth about how much they should increase the diuretic medicine, Furix. After that they spend quite some time discussing side-effects and whether Karl should try to decrease another drug, Cordan. Several times they consult the medication profile in prototype-print out for the time and the quantity taken.

Now, the part of medication management, which involves meeting clinicians and discuss symptoms and side effects, has been reconfigured. First of all, the cardiologist encourages Karl to be an active participant i.e. he values getting Karl's notes and medication profile before the meeting. In addition, a new actor – the prototype – has found its place mediating the discussion around medication. They both use it several times to guide the conversation and get reassurance about certain things. It is not only Karl's explanation that counts it is moreover the prototype and what is printed on it. What is interesting in terms of the ethnography-design relation, is that when Karl or the cardiologist point at the prototype, talk about it or use it to guide the conversation, they at once mobilize earlier ethnographic practices (the interview guide, the working papers, the implications for design where "medication management" was made 'visible') and participatory design (the cardboard game, Niels' home made laminated plastic card with a medicine list, the patient's written medicine list from using the first prototype and the web developer's PHP code). However, in the situation, these two disciplines come together. One is not without the other. In the design intervention, medication management is different than without the prototype.

So far so good. Now to the proactive engagement of ethnography and participatory design in the design intervention. At this point in time, the 'Assignment' feature

and the related ethnographic discourse on patient work has therefore not been connected to medication management in any situation of use. 'Home work' is still (only) an analytical category. Also, the participatory design or re-design of the prototype or use of it has not been actively engaged. After almost an hour, the meeting has come to an end and the cardiologist stands up while talking. The design researcher sees his chance and speaks for the first time: *"There is one more thing. We've created something we call 'assignments', which are a little experimental, but in your discussion with Karl you indirectly ask him to do some tasks – that he must keep an eye on this and that – so, what should he enter in the prototype for your next meeting?"* The cardiologist quickly gets the idea and immediately asks Karl to write down (in the prototype), everyday if possible, how long he can walk. This would be helpful in relation to his breathing. The design researcher: *"And then there was something in relation to the medication – something with Furix?"* and the cardiologist says: *"Yes, the weight, walking distance, weight and blood pressure. Clearly it would be a great help to have"*.

They end the conversation and shake hands and Karl and his wife leaves. The cardiologist sits down and says he just needs to finish off and make dictate a summary for the medical record. He picks up the tape recorder and dictates: *"Memorandum to Karl.... Meets for medical consultation. Full stop. See the above. New line. Since the last meeting. Colon. [the cardiologist looks at the prototype print-out] Complaints of oppression, unpleasant upper abdomen [almost exactly as the first line of Karl's writing]... We try RECIPE CRESENDO [prescription, gradually increase] tablet FURIX to 40 mg x 2 plus KALEROID 40 mg x 2. Daily weight measurement and assessment of walking distance a few times a week. Full stop. Signed [cardiologist name]"*.

In these last minutes, the design researcher intervenes and connects Karl's and the cardiologists discussion around Furix (bloated stomach) to a participatory design experiment and ethnographic curiosity; "could Karl and the cardiologist possibly want to collaborate in new ways?", "Do they like this feature at all?", "what are the consequences of increasingly extending patient responsibility and active participation?", "How could homework make sense for both patients and cardiologists?". By the design interventionist move of suggesting to use the prototype to collaboratively monitor the increase in Furix, the toolbox of participatory design is enacted but in one and the same moment, proactive analysis is enacted. It goes a bit further because what happens is that the cardiologist agrees with Karl to try to monitor his weight since it is highly related to the increase in the dose of Furix. And as he says: *"Clearly it would be a great help to have"*. The "Daily weight measurement" agreement or 'Assignment' moreover materializes in the hospital's medical health record through cardiologist dictating it. And later, which is out of the scope of this paper, it materializes in the

prototype by Karl using the prototype to monitor himself and share it. By design interventions with the prototype, the ethnography-design relation is blurred and a transcended, proactive way of interdisciplinary engagement has taken place.

CONCLUSION

The methodological problem, which this paper departs upon, concerns the much debated relation between ethnography and design. We frame the underlying problem as being a matter of creating unnecessary disciplinary boundaries. Some argue for the fruitfulness of employing ethnography as its principles prescribes [e.g. 3, 11], thus creating a disciplinary dichotomy, while others suggest to integrate ethnography and participatory design as ways to develop CSCW "in practice" [9], create a "shared practice" [17], and perform reflexive relations between understanding and designing ("design interventions") [34]. To a large extent, we have carried out the same kind of activities as suggested in the latter lines of work. That is, critically integrating ethnography and participatory design as part of a collaborative work domain in healthcare. But what we have also done, is shown how ethnographic work and participatory design can become co-constitutive of the making of "medication management".

Without the interview guides, working papers, and "implications for design" (which traditionally conforms to ethnography in CSCW) and without the cardboard design game, the patients using the first prototype, and the developer writing PhP code (usually appointed as participatory design activities) medication management, as accounted for in this paper, would not have existed. But more important, by example of a design intervention, we suggest the fruitfulness to disregarding the disciplinary divide and instead consider them as mutually constitutive. We advocate an ontological shift, as is happening in broader lines of social science [5], and to engage ethnography-design relations in proactive ways, making the divide converge. Working towards dissolving the disciplinary dichotomies, is in many ways a novel response to Schmidt and Bannon's [31] programmatic suggestion of exploring how studies of cooperative work relations might be exploited in the design of useful CSCW systems.

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